

# Health Care Ethics USA

A resource for the Catholic health ministry

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# Three Revolutions: Healing, Power and Ethics

*Editor's Note: In observance of the 100<sup>th</sup> anniversary of the Catholic Health Association, Johnny Cox, who is one of the earliest ethicists in Catholic health care, was asked to reflect on his experience. That reflection follows.*

Johnny Cox, RN, Ph.D.

Sponsor

Providence Ministries

[Johnny.cox@providence.org](mailto:Johnny.cox@providence.org)

Indiana Jones, Luke Skywalker and Frodo Baggins couldn't have encountered more adventures than faced me during thirty years doing ethics in American Catholic health care ministry. Like their fictional challenges, most of mine were encounters with power. Power that heals and power that harms, intermixed nearly daily. Thank God, the Force is with us! In my view, three revolutions have tilted the balance of power in favor of healing, two on the edges of life and one central to our Church and professional milieu.

## Birth

Our first baby was due in mid-May and my dissertation defense was scheduled for mid-July. 1972 was an exceptional year. Both these events concerned health care ethics, one quite theoretical and the other very, very personal. After all, what could be more personal than childbearing?

Among the many surprises during the months of pregnancy was that only a single physician in that California community had leveraged the local hospital into allowing fathers into the delivery room. My wife and I wanted a family birthing experience so our choice was obvious. The obstetrician was competent,

seemed quite sensitive and made it clear to me during the introductory visit that his professional relationship with my wife did not have room for me! I saw him next while I stood at the opposite end of the delivery table, watching through mirrors as our son was delivered.

My first experience of the power of medicine to fashion the meaning of profound life experiences was only okay. I was thrilled to be there watching a miracle. I participated by coaching and encouraging and being silent as I'd been instructed in Lamaze classes. Joy prevailed. Still something felt incomplete, although I couldn't put my finger on it. Insight began with the next pregnancy.

A year later in another state with an obstetrician who encouraged me to accompany my wife to office visits, a curtain was raising on the medicalization of child birthing. He inquired how I was doing with the pregnancy, anticipating a second child pretty soon after the first. He always provided private time for my wife. He clarified safety parameters and offered options that included a birthing center and nurse midwives. Other family members could participate, if we wanted. Basically this physician used his professional power to fashion gestation and birth as family enriching experiences. Little did I know just how much of a revolution was underway.

That light dawned three years later during my obstetrical rotation as a student nurse. I was assigned to a community hospital in a suburb of a major metropolitan area. The grassroots family birthing revolution was taking off, but at this hospital almost all delivering women were anesthetized and the babies were delivered with forceps. Naively, I inquired of my professor why this practice persisted; she stated the physicians preferred to practice the way they had been trained. I objected that our course textbook taught this previous protocol was no longer scientifically indicated. She looked at me with an expression that spoke volumes. Welcome to the real clinical world of power, politics and ethics. A popular contemporary text examining the first years of nursing was titled *Reality Shock*.

Fortunately, by the end of the seventies, hospitals and physicians were trying to outdo one another on family-friendly processes and environments for carrying and delivering babies. This radical shift of power from the medical establishment to moms and dads occurred just as bioethics was emerging. This revolution catalyzed two important transitions that are unfinished today, one for patients and the other for staff.

The civil rights movement was impacting medical paternalism. In 1973, the American Hospital Association developed its *Patient's Bill of Rights*. The agitation of the 1960s had highlighted disparities between ethical principles and professional practice. The first Directive of CHA's 1949 *Code of Ethical and Religious Directives for Catholic Hospitals* reads: "Even the procedures listed in this section as permissible require the consent, at least reasonably presumed, of the patient or his guardians. *This condition is to be understood in*

*all cases*" (emphasis in original). But, to modify a currently popular phrase, culture eats principles for lunch! Patients and families docilely followed orders which they presumed, usually correctly, were in their best interests based upon the physician's expertise and beneficence. Many still do but there's been remarkable progress toward patient-centered systems and processes in clinical services. The Internet and electronic medical records help those who use them. Nevertheless today's daily ethical issues in clinics and hospitals challenge us to support patients in exercising their proper decision making prerogatives.

The staff version of patient-centered successes followed a similar trajectory. As I was entering the field, the authority of the physician was akin to the captain of a ship whose word was law. Vestiges of the American hospital's naval roots still include house officers and, of course, orders. Fifty years ago the sailors – nurses, pharmacists, therapists – were expected to salute and obey orders. But then the sailors became officers who were held accountable for their own decisions. Judges no longer accepted the defense that "I followed the doctor's orders." Practice standards and licensure requirements bolstered their professional status and accountability. But they lacked institutional support.

At that time, many if not most, ethics committees allowed only a physician to request an ethics consultation. Through a pioneering policy in 1983, the medical center where I worked gave nurse managers authority to convene mandatory ethics conferences for patients on their units. Within a month, the highest admitting surgeon announced quite loudly that he would not attend a conference

on one of his patients that the nurse manager had scheduled for the next morning. In a way, a gauntlet was thrown. I brought his proclamation to the CEO, who was a living legend of leadership, and listened to her phone call with the surgeon. She simply stated, “Doctor, I understand important decisions for one of your patients will be discussed tomorrow morning. I’ll see you there.” He came. And the word got around. Sadly our three decade track record is, at best, spotty. Once again we find ourselves in the wide gap between principle and practice. In 1992 the first edition of the American College of Physicians *Ethics Manual* stated forthrightly that in ethical matters “even though health professionals have special areas of expertise, each member of the patient care team has equal moral status.” The physician is still captain, but captain of a team of professional colleagues. This conviction is taproot of a culture of mutual respect among professionals that keeps patients at the center of decision making.

Twenty-five years later I am gratified by organizational progress in developing cultures of collaboration and accountability, mostly driven by patient safety and quality initiatives. I am also concerned by the continuing struggles to maintain the gain. Strengthening this culture shift continues to be my top priority.

## Death

I stepped into the next revolution during a speaking engagement in 1974. Another speaker was Florence Wald, dean of the Yale School of Nursing and co-founder of America’s first hospice. She raised the curtain on the medicalization of dying and

encouraged me to start a hospice. I was in my twenties and an assistant professor of theology. Within two years Hospice Maran Atha was offering a distinctive way of supporting families to care for their loved ones with terminal illnesses in Spokane, Washington. It was the first hospice providing clinical services in the Northwest and one of the first dozen in the country.

Hospice pioneers introduced a concept of caring, a way of restoring dying persons to homes and families. The goal was not to launch a new health care specialty service but to restore the *ars moriendi*; our message to the community was that dying is a simple, delicate family affair. We sought to integrate this way of caring into existing hospital services but were rebuffed by a medical model of treating disease and the power of vitalism that denied dying as a phase of living.

About the same time, my first years in clinical ethics were also a marathon swim against the swift current of forces that equated the purpose of medicine with treating disease to keep people alive. The stories were poignant. There was a pulmonologist who withdrew from treating a patient on conscience grounds. The patient asked for “comfort only,” the nephrologist and cardiologist agreed “there was nothing left to do.” But the pulmonologist insisted she was professionally obligated to treat the lung infection because it was reversible. There were also those doors to the surgery department beyond which all patients would be resuscitated, no exceptions! Twenty-five years later and closer to home found my mother, an eighty-seven year old with a slowly decompensating heart, who wanted a fairly simple treatment that promised her more strength, but who did not

want to be resuscitated if anything went wrong. The treatment went uneventfully but mom developed a complication and was transferred to the ICU. The nurse manager noted her DNR status and said it would have to be rescinded. My brothers, the priest and clinical social worker, and my sister, the cardiac critical care nurse, held firm. The cardiologist was paged to the unit and declared, “Everyone in this ICU is full code.”

This was a Catholic medical center in 2009. No matter that ethical principles and legal requirements about consent were now clear, no matter that such a practice exposed the professionals and facility to liability risks. The culture of vitalism prevailed. My sophisticated family was adamant and the physician relented. Think of the countless others who were not so fortunate.

Ironically, some years before I had done ethics education on life-sustaining treatment for staff in that very ICU. My family’s experience reinforced the mantra of my friend and colleague, Jack Glaser, that “to educate and hope is a futile strategy.” Without solid organizational architecture, complete with policies and protocols, and courageous executive power to assure accountability for our moral commitments, educational efforts are like seed thrown on rocky soil that looks good when it sprouts but withers as soon as opposition arises. Last year’s report of the Institute of Medicine on *Dying in America* highlighted roughly the same issues and priorities that were front and center in the 1980s.

The power of vitalism is antithetical to the scriptural and theological foundations of our mission as healing ministries of Jesus Christ.

In 1980 the Congregation for the Doctrine of the Faith’s *Declaration on Euthanasia* warned “Today it is very important to protect, at the moment of death, both the dignity of the human person and the Christian concept of life, against a technological attitude that threatens to become an abuse, denying the right to die peacefully with human and Christian dignity.” The recent successes of palliative care programs and services are remarkable precisely because the medical model of treating disease and a culture of vitalism remain deeply embedded in Catholic health care. We are making progress but old habits and new threats persist. Do we name vitalist behavior as social sin? How are our executives supporting physician leaders to curtail those behaviors? Are our oncology groups encouraging drugs that might extend life by a few months rather than suggesting hospice care? How are we applying the principles governing toleration of evil within our own acute care facilities and specialty clinics?

The revolution of restoring the *ars moriendi* to patients and families in their own communities has undeniably progressed. The contemporary shift from hospital-centric treatment to population health offers tremendous opportunities for renewing our commitment and investing additional resources. This is a key ethical challenge for the current generation of Catholic ministry leaders.

### Conscience

Saint John XXIII opened the Church window that ushered in the breeze igniting the fires of the third revolution. Among its many achievements, the Second Vatican Council

resurrected Catholic tradition about conscience from a century in the tomb of nearly blind obedience to authority. *The Church in the Modern World* proclaimed, “Conscience is the most secret core and sanctuary of a man. There he is alone with God, whose voice echoes in his depths....In fidelity to conscience, Christians are enjoined with the rest of men in the search for truth, and for the genuine solution to the numerous problems which arise in the life of individuals and from social relationships” (16). In 1976, the U. S. bishops reinforced this renewal of Catholic tradition in their pastoral reflection on the moral life, *To Live in Christ Jesus*: “We live in good faith if we act in accord with conscience. Nevertheless our moral decisions still require much effort. We must make decisions of conscience based upon prayer, study, consultation and an understanding of the teachings of the Church” (p. 10).

Even though the following three decades were filled with powerful attempts to squelch these revolutionary fires within the Church, by 2005 nearly every U. S. Catholic health system had established some version of communal conscience formation. Formal discernment protocols or ethical decision making processes were hardwiring our tradition’s teaching on forming conscience within ministry communities. While ordinarily a particular person or group is accountable for a specific decision and its consequences, our tradition emphasizes reaching the decision in community through study, reflection, consultation and prayer together. The richness of our heritage resides within the persons who make up our communities of healing. The wisdom of the Spirit dwells in each and every one gathered together.

Ethicists and moral theologians were simultaneously expanding their repertoire of services into health care board rooms, executive suites and business offices as facilitators for forming organizational conscience and reaching decisions on key issues. The process I helped create and introduce into a Catholic health care system fifteen years ago has three phases, each intended to channel the power of leaders into genuine communal deliberation. Exercise of power is crucial! The first is assembling the appropriate community of reflection to assure those persons and groups who have insight and will be affected by the potential decisions participate. Many leaders tend to exaggerate their own capacity to represent various perspectives, consequently using their power of selection to exclude crucial voices and prejudicing the deliberation. The second phase is the actual decision making process that assures the conversation is focused and participants can share their insights safely and be heard. Some leaders use their power to preempt agendas and even intimidate participants. The third phase is implementation with designated metrics and assigned accountabilities, including a communication plan. It’s a moral imperative to be vigilant against the power to undermine or impede implementation either by opposition or neglect, in effect making a mockery of the entire conscience formation process.

In the present environment, in which Catholic health care is often viewed as an industry or merely a business, it is more important than ever that decisions made by faith-based health ministries are grounded in their communal heritage and moral tradition.

To reach a significant organizational decision without diligent use of an ethical decision making process constitutes moral negligence.

The battle for the healing ministry's soul rages fiercely. The Spirit is at work with and within those gathered to make decisions fashioning the identity and vitality of our ministries. The tools and processes are in place to continue the revolution started by Saint John XXIII. Today's ministry leaders must use their power to fend off current internal and external threats to conscience, the most secret core and sanctuary of healing ministries.

### **New Revolutions?**

So these three revolutions continue with the intermixed powers to fortify and powers to erode Catholic health care ministry. Challenges abound, and who knows what new revolutions are emerging? Whatever arises, patients and their families will need the ministry's support to keep them central to decision making and to integrate the meaning of their health care experiences into their lives – whether birthing, dying or anything in between. Genuine whole person care! Staff, too, will flourish as *moral equals* in decision making and caring only with the support of executives who consistently maintain accountability for organizational conscience through its policies and protocols. True communities of professional integrity! Prayerful discernment processes involving the appropriate community of reflection will keep the Spirit at the heart of strategy and particular decisions to advance the healing love of Jesus. Catholic ministry at its best!

St. Paul reminded the ministry leaders of his day (2 Tim. 1:7) that “God did not give us a spirit of cowardice but rather of power and love and self-control.” Same today and tomorrow, onward into new revolutions. Thank God, the Force is with us!

*Johnny Cox is a moral theologian and registered nurse who started serving Catholic health care in 1973. He is also sponsor, Providence Ministries.*

# Lessons from Gerald Kelly, S.J., the Father of American Catholic Medical Ethics

*Editor's Note: The following essay was submitted as part of the 2014 Graduate Student Essay Contest sponsored by CHA in conjunction with the annual Theology and Ethics Colloquium. It is being published at this time to mark CHA's 100<sup>th</sup> anniversary, given Gerald Kelly's significant contribution to Catholic health care ethics.*

Kate Jackson  
Ph.D. Student in Theological Ethics  
Boston College

## I. Introduction

At a time when health care and Catholic health care are undergoing such profound changes, it is helpful to reflect on where Catholic health care ethics has been, how this history shapes the present situation, and what lessons this history might impart on Catholic health care ethicists moving forward. The prolific writings of Gerald Andrew Kelly, S.J. (1902-1964) on the intersection of medicine and moral theology position him as the “father of medical ethics.”<sup>1</sup> A Jesuit priest, a close friend of the controversial figure John Ford, S.J. (1902-1989),<sup>2</sup> the “inventor” of the *Moral Notes*,<sup>3</sup> the brain behind the first “Code of Ethical and Religious Directives for Catholic Hospitals,”<sup>4</sup> the clarifier and promulgator of ordinary and extraordinary means in end-of-life issues,<sup>5</sup> an avid follower of Pius XII's (1876-1958) many decrees, and a staunch opponent of birth control, Gerald Kelly left a mark on Catholic history and Catholic medical ethics. This paper is an inquiry into the contributions of Gerald Kelly to the beginnings and shaping of modern American Catholic medical ethics and into what Catholic health care ethicists might learn from this complex figure. Through his

groundbreaking work and his influential role in crafting the early iterations of the “Ethical and Religious Directives,” Kelly navigated a path of bioethical reflection that took seriously biology, theology and, when applicable, magisterial decrees. I will assess his differing modes of bioethical reflection through an analysis of three medico-moral topics: end-of-life care, mutilation in light of the principle of totality, and artificial insemination. These cases offer insights about the early stages of Catholic bioethics. From these topics, we see the evolution and refinement of notions of ordinary and extraordinary end-of-life care. We also learn about early approaches to interpreting magisterial decrees. Kelly interpreted magisterial and papal decrees with similar concerns, commitments, and challenges that CHA faces today when interpreting the ERDs and bishops' statements. Re-evaluating Kelly's approaches provides two benefits: knowledge of a part of the Catholic health care ethics tradition, and lessons from a historical figure who provides insights to Catholic health care ethicists for how to (and

how not to) face modern magisterial interpretation challenges.

## II. Biography<sup>6</sup>

Gerald Andrew Kelly was born in the “Irish Catholic ghetto”<sup>7</sup> of Denver, Colorado, to parents Andrew Kelly (from Chicago) and Mary Higgins (originally from London), on September 30, 1902. He was one of five brothers and one sister. After attending a Jesuit high school in Denver, Kelly joined the Jesuit novitiate in Florissant, Missouri, on August 8, 1920. He earned a B.A. at Mount St. Michael’s College in Spokane, Washington in 1927.

Following these studies, from 1927 to 1930, Kelly moved to St. Mary’s Kansas where he was the prefect of a boarding school within St. Mary’s, a Jesuit-run high school and college. This experience was the source of material for his first publications—adventure stories entitled *Terry Donovan* (1930), *The Din of Battle: The Story of Fr. W. Doyle, S.J. (1931)*, *The Four Knights* (1931), and *Peanut the Big Little Man* (1937).

In 1930, Kelly moved to Saint Louis University, only to return that year to Kansas and to St. Mary’s, which, due to financial hardships of the Depression, had been turned into a Jesuit theologate called St. Louis-St. Mary’s, dedicated to education during the latter portion of Jesuit studies. He stayed there until 1933 when he was ordained. From 1933-1935, he studied in Cleveland, Ohio, at St. Stanislaus Novitiate, and he began studies at the Gregorian University in 1935. Kelly’s time in Rome culminated on March 22, 1937, with the publication of his dissertation that would prove informative in his thought.

During this time in Rome, Kelly received extensive training in canon law, met his future friend and colleague, John Ford, S.J. (1902-1989), and furthered his interests and methods in medical ethics. Kelly’s thesis, *The Theologians’ Concept of Venereal Pleasure* was highly influenced by the thought of Francis Hurth, S.J. Interestingly, Hurth was rumored to have been crucial in the formation of Pius XI’s papal encyclical, *Casti Connubii* (1930).<sup>8</sup> Like much of his later work, Kelly’s dissertation was a robust survey of the various uses of a contentious term (in this case, “venereal pleasure”), demonstrating Kelly’s fluency in historical and contemporary moral theology, as well as in the principles of biology. The survey methodology of his dissertation would influence his approach to moral questions thereafter, and his conclusions would influence his later and very popular 1942 publication, *Modern Youth and Chastity*.

After completing his dissertation in 1937, Kelly returned St. Mary’s College in Kansas for what would be a 27-year tenure as professor of moral theology at, what was then, a Jesuit Seminary. As a scholar, he was quickly recognized for his extensive surveys of moral and medical literature—a broad knowledge base organized and kept straight by the large “card-index” collection of authors and arguments that he was known to keep.<sup>9</sup> From 1941-1954, with John Ford, Kelly initiated and wrote the “Notes in Moral Theology” in *Theological Studies*.<sup>10</sup> Additionally, his work was distributed through a variety of publications, including *Theological Studies*, *Review for Religious*, *Linacre Quarterly*, and *Hospital Progress*, as well as the books *Medico-Moral Problems*<sup>11</sup> and *Contemporary Moral Theology*.<sup>12</sup> Kelly wrote

on controversies as they arose, ensuring that his work was relevant to his time. Kelly wrote prolifically until his death in 1964.<sup>13</sup>

### III. Kelly's Work on Medical Ethics

#### *Overview of Kelly's Method*

After years of commenting on ethical issues, Kelly clearly articulated his notion of the role of the moral theologian, and the hermeneutics that a moral theologian should use, in his 1956 article, "The Morality of Mutilation: Towards a Revision of the Treatise," in *Theological Studies*.<sup>14</sup> For Kelly, the role of the theologian was tripartite. Kelly stated in the article that the theologian, like the faithful, must "give the required assent" to magisterial teachings, "incorporate them into his teaching and his writing," and then explain and interpret the teachings.<sup>15</sup> His easy acquiescence to the magisterium was reminiscent of the attitudes of his predecessors. It is notable that today's posture towards the magisterium is probably one that is more eager to engage in debate. Kelly also provided "norms for interpretation."<sup>16</sup> He explained that the theologian must study the "verbal formulas" of papal pronouncements, keeping in mind that "the words themselves may fail to express the mind of the Holy See."<sup>17</sup> Second, the theologian must study the "historical setting" of the pronouncement in order to assess the issues the Pope was trying to settle with the pronouncement.<sup>18</sup> In this way, one could determine the scope of the decree. Throughout his work, Kelly was careful to ensure that his interpretation did not exceed or diminish the Pope's intent.<sup>19</sup> Third, Kelly looked at the controversy and the extent to which a papal decree settled a matter. Kelly assumed the Pope was aware of

controversies and so an absence of papal clarity indicated the appropriateness of a diversity of opinions.

Also integral to Kelly's method (but problematic to moderns) was to worry about the conscience of doctors and their "limited" ability to think through moral decisions. Kelly was paternalistic towards doctors as he sought not to burden their consciences with overly complex moral paradigms. Thankfully, at least, he left medical choices to their discretion. Kelly thought extreme ethical positions and rigid ethical guidelines would be more lenient on doctors' consciences because the course of action was clear and thus required less discerning on their part.<sup>20</sup>

#### *Ordinary and Extraordinary Means*

A particularly helpful and enduring insight into medical ethics was Kelly's clarification of the distinction between ordinary and extraordinary means in end-of-life care. As Jim Keenan astutely notes, Kelly's classicism and his strong admonition against killing made space for him to entertain many possibilities in end-of-life care.<sup>21</sup> Kelly's views on this were clearly articulated in the 1950 article for *Theological Studies*, "The Duty of Using Artificial Means of Preserving Life," wherein he concluded that futile, ordinary procedures are not morally obligatory during end-of-life care. Kelly further clarified the distinction in the 1951 article for *Theological Studies*, "The Duty to Preserve Life," wherein he stated that usefulness is the criterion that should be used to differentiate ordinary from extraordinary means. He also acknowledged the importance of accounting for burden and exercising prudence in end-of-life decisions.

In “The Duty of Using Artificial Means of Preserving Life,” Kelly surveyed the varying opinions of moralists on end-of-life treatment and then offered his personal stance. He noted that although moralists used the terms “ordinary” and “extraordinary” means, “they do not always define these terms.”<sup>22</sup> Despite the lack of precision, Kelly found that moralists held similar understandings of the terms and so he concluded: “By *ordinary* they mean such things as can be obtained and used without great difficulty. By *extraordinary* they mean everything which involves excessive difficulty by reason of physical pain, repugnance, expense, and so forth.”<sup>23</sup> In this way, fellow theologians provided the basis for his understanding of the issue.

Kelly said that few authors cited what specific procedures were considered ordinary, but if they did, they characterized ordinary as the “use of reasonably available food, drink, medicines, and medical care; the wearing of sufficient clothing; the taking of necessary recreation; and so forth.”<sup>24</sup> After this survey he concluded:

[T]he following are commonly accepted principles: *Per se* he is obliged to use the ordinary means of preserving his life. *Per se* he is not obliged to use extraordinary means, though the use of such means is permissible and generally commendable. *Per accidens*, however, he is obliged to use even extraordinary means, if the preservation of his life is required for some greater good such as his own spiritual welfare or the common good.<sup>25</sup>

So then, extraordinary means were appropriate and even “laudable,” but not

morally obligatory.<sup>26</sup> In the case of the terminal coma, Kelly affirmed that “non-use of artificial life-sustainers is not the same as mercy killing” and “the artificial means not only need not but should not be used, once the coma is reasonably diagnosed as terminal.”<sup>27</sup> In this way, he affirmed that extraordinary measures are not morally obligatory.

Kelly proceeded to differentiate between artificial ordinary means and non-artificial ordinary means, and concluded that artificial ordinary means may not be obligatory if the efforts are anticipated to be futile or nearly futile.<sup>28</sup> Artificial ordinary means were also not obligatory when the goal is short-term and only “to prolong life a short time.”<sup>29</sup> As such, “since it is artificial, and since it has practically no remedial value in the circumstances, the patient is not obliged to use it.”<sup>30</sup> He said that intravenous feeding in order to extend one’s life for a few weeks is an ordinary means, but it may not be obligatory in light of these criteria.

He then added the virtue of prudence and the quality of burden as factors to consider in this distinction. Kelly worried that ending intravenous feeding may “appear to be a sort of ‘Catholic euthanasia’ to many who cannot appreciate the fine distinction between omitting an ordinary means and omitting a *useless* ordinary means.”<sup>31</sup> He acknowledged that a doctor might feel compelled to feed the patient in order live up to a professional ideal, but that the expression of the ideal required “prudence.”<sup>32</sup> Finally, he added the criterion of burden. He stated that one is not morally obligated to incur or advise “intolerable burdens on patients or relatives.”<sup>33</sup> So then it is up to the doctor and family to assess the

most prudent and least burdensome way to proceed. In this way, Kelly built a case for the distinction and qualified it with the helpful criteria of uselessness, artificiality, and burdensomeness.

While the 1950 *Theological Studies* article stated that artificial ordinary means of end-of-life care were not morally obligatory when they were essentially useless, Kelly simplified his view in the 1951 “Notes.” In the revision, he said that the discriminating factor between ordinary and extraordinary is usefulness. So then, what was considered useless ordinary artificial means in 1950 was considered extraordinary according to the 1951 article (in both cases the procedure would not be morally obligatory). In the 1951 iteration, Kelly stated that “usefulness” is an important criterion of what makes something ordinary. The impetus of the revision was the Sanders case where a physician inserted an air bubble into a cancer patient.<sup>34</sup>

Kelly’s revised definition is as follows:

*Ordinary means* are all medicines, treatments, and operations, which offer a reasonable hope of benefit and which can be obtained and used without excessive expense, pain, or other inconvenience.

*Extraordinary means* are all medicines, treatments, and operations, which cannot be obtained or used without excessive expense, pain, or other inconvenience, or which, if used, would not offer a reasonable hope of benefit.<sup>35</sup>

With useful as the operative category, ordinary means were obligatory and extraordinary were not. However, Kelly noted the possibility that extraordinary could be

obligatory if the common good or “eternal salvation” was at stake, although he did not elaborate on what that meant.<sup>36</sup> From his methodical analysis of the issue, free from constraints of the magisterium, we see how Kelly was able to offer a robust and practical paradigm for end-of-life care.

### *Principle of Totality*

In 1955, Kelly expounded on the principle of totality in his article for *Theological Studies*, “Pope Pius XII and the Principle of Totality,” by unabashedly looking exclusively to Pope Pius XII. In this piece, Kelly investigated the use of the principle of totality regarding modern problems in bioethics—sterilization, transplantation, and experimentation. In the 1956 follow-up article, he refined his stance on mutilation by further explaining blood transfusions, castration, cesarean sections, experimentation, fallocotomy and vasectomy, hysterectomy, lobotomy, and transplantation.

Kelly began his inquiry with an assessment of the major papal uses of the principle. Kelly stated that Pope Pius XII’s September 13, 1952 address to the “First International Congress on the Histopathology of the Nervous System” was the first time Pius used the term “principle of totality.” Kelly noted that the principle was originally worked out in St. Thomas and referred to by Pius XI (1857-1939) in 1930 and Pius XII in 1944.<sup>37</sup> Kelly then investigated the principle not via an examination of the evolution of Thomistic thought, but rather by looking to the popes. Kelly first discussed Pius XII’s understanding of the difference between the physical whole and the societal moral whole. Kelly deemed the following as the “best-known formalization” of the principle, articulated by

Pius XI: “And they are not free to destroy or mutilate their members, or in any other way render themselves unfit for their natural functions, except when no other provision can be made for the good of the whole body.”<sup>38</sup>

He then used papal talks as the basis to answer three questions:

- (1) How does the principle of totality apply to the ordinary problems of medicine as outlined in the Code of Medical Ethics for Catholic Hospitals?
- (2) How does the principle of totality affect medical experimentation on human beings?
- (3) Does the principle of totality exclude organic transplantation?<sup>39</sup>

In the first talk, Pope Pius XII distinguishes between, what Kelly called, “the physical entity and the moral entity.”<sup>40</sup> Kelly came to his position from Pius’ assertions that “[o]utside the organism it [an organ] has not, by its very nature, any sense, any finality. It is wholly absorbed by the totality of the organism to which it is attached,” as opposed to how an individual relates to the moral community.<sup>41</sup> As Kelly pointed out, Pius XII was very concerned about the individual being subsumed by the state. Kelly was sure to stress that an organ functions differently than an individual in a community. An individual, unlike an organ, has an end beyond and apart from the community.

Kelly explained that, to the urologists, Pius XII was clear that the principle of totality, in regards to organs, should be evaluated in light of the whole body of the individual so that “[t]he decisive point here is not that the organ which is removed or rendered inoperative be itself diseased, but that its preservation or its functioning entails directly

or indirectly a serious threat to the whole body.”<sup>42</sup> Pius XII clarified that the principle of totality does not discriminate against the type of organ, only that it can be destroyed if it puts the whole body at risk.

Kelly then identified an ambiguity in the pope’s teaching and used the most reasonable interpretation to rectify the problem. Kelly noted the difficulty in trying to understand Pius XI’s iteration (echoed in its awkward double negative formulation by Pope Pius XII as well, Kelly said) of the principle of totality: “That individuals have not the right to mutilate their bodies ‘except when no other provision can be made for the good of the whole.’”<sup>43</sup> Kelly stated that the most “literal” interpretation of this “leads logically to the embarrassing conclusion” that one might treat something like a gall-bladder pathology with a restrictive diet, instead of the more efficacious cholecystectomy.<sup>44</sup> He concluded that neither pope would have wanted to say that an organ takes priority over the body, and so we must interpret the word “necessity” broadly. He added that hysterectomy was morally permissible in order “to prevent the recurrence of cancer” because it is in-line with “the statement of Pius XII that mutilations are permitted ‘to avoid...serious and lasting damage.’”<sup>45</sup> Kelly interpreted Pius XII in the way that would make the most sense in light of what Kelly saw as Pius’ objectives.

Kelly then briefly noted that the principle of totality was not applicable when a pregnant woman’s life was at risk because the fetus is not one part of a whole, but rather its own whole. Kelly suggested using the principle of double effect in such a scenario, noting two salient issues that ought to be considered when making this decision: “(a) whether the

treatment helps the mother without directly harming the fetus; and (b) whether there is a proportionate reason for using the treatment before the child can be safely delivered.”<sup>46</sup>

On the issue of human experimentation, Kelly set out to clarify the “obscure” statements within Pius XII’s remarks against experiments.<sup>47</sup> As tools for interpretation, Kelly used the Pope’s clear declarations on the issue, the context of the papal statements, and the “actual practice of clinical investigators and research workers in the field of medicine.”<sup>48</sup> He first acknowledged the historical problems that influenced the Pope’s teaching. As such, Kelly described the problems of totalitarianism and individualism that the Pope would have been thinking about. He said that it was “unsound” to overly extend what Pius meant by experimentation.<sup>49</sup> Kelly concluded that Pius XII might allow for the possibility that minimally risky experimentation was permissible. Kelly took the moderate view that the Pope was not speaking against all types of human experimentation, but rather that he was against experimentation when the risk was disproportionate to the outcome.

### *Artificial Insemination*

Kelly was supportive of artificial insemination and articulated his view in 1939 and in 1947. Despite his positive view towards the treatment, he retracted his position in 1949 after Pope Pius XII declared it morally impermissible. In 1939, in “The Morality of Artificial Fecundation” published in the *American Ecclesiastical Review*, Kelly surveyed the debate on artificial insemination, citing the Vatican’s 1897 condemnation of masturbation and insemination that relied on

masturbation, and over 30 moralists’ varying opinions.<sup>50</sup> In this article, Kelly clearly supported artificial insemination within the bounds of marriage. He justified his position with the following logic, as described by scholar Edwin Lisson, S.J.: “the basic marital right to the use of the body which was parallel to the basic right of self-preservation.”<sup>51</sup> Kelly asserted that there was nothing confining procreation to, as Lisson describes, “normal sexual intercourse.”<sup>52</sup> As evidence, he used the notion that semen extraction for the purposes of health examination was permissible. Kelly admitted that the Holy See was vague regarding whether married couples “do not possess in common a right to propagate which allows them, by mutual consent, to have recourse to some extra-ordinary means of propagating which is not in itself sinful.”<sup>53</sup> In light of the ambiguity, Kelly saw a space to formulate a personal conclusion and acted accordingly.

Kelly reaffirmed his position in the 1947 article, “Moral Aspects of Artificial Insemination” for the *Linacre Quarterly*. He was aware that there was a myriad of opinions on this issue and he stated that until the Vatican clearly banned artificial insemination, it was a licit act. Both Kelly’s stance on the issue and his deference to the Vatican were made clear in the following statement: “In practice, until the dispute is settled [by the Holy See], Catholic doctors may follow the opinion that artificial insemination between husband and wife is permissible if the husband’s sperm can be obtained in a morally unobjectionable manner.”<sup>54</sup> Regarding the appropriate manner of sperm donation, Kelly added that masturbation is not permissible. In this way, Kelly both affirmed his position

and made it clear that the pope has final authority.

After Pius XII clarified his stance, Kelly quickly changed his opinion to match Pius XII's. On September 29, 1949, at the Fourth International Congress of Catholic Doctors, Pius XII stated that extracting semen was permissible for medical sterility exams, but not for artificial insemination. Within a year, Kelly acknowledged the change and publicly revised his stance in the "Notes on Moral Theology" in 1949. In the "Notes," he referred to Pius XII's September 29, address and said that, at that time, "Pius XII gave a general outline of the correct moral teaching on artificial insemination."<sup>55</sup> As Lisson notes, the new position was reflected in all of Kelly's writings thereafter. Rather than critically assess the Pope's position and its relationship to Kelly's prior positions, Kelly submitted to the new position.

#### IV. Reception

During his time, amongst lay people and where guidance was needed, such as in areas of education and hospital ethics, Kelly's thought was very influential. He made a huge impact in medical ethics through his work with the Catholic Hospital Association. Kelly began writing on moral medical dilemmas in 1947 for the *Hospital Progress*, a journal of the Catholic Hospital Association.<sup>56</sup> Twelve of these articles were compiled and published in 1949 as the pamphlet, "Medical-Moral Problems (Volume 1)." In 1954, five pamphlets made from Kelly's work in *Hospital Progress* and *Linacre Quarterly* were published as the book, *Medical Moral Problems*.<sup>57</sup> In 1949, the Catholic Hospital Association released the nine-page pamphlet, "The Code

of Ethical and Religious Directives for Catholic Hospitals," and it offered a much more comprehensive list of directives than anything that had been published previously. Lisson surmises that the document was "composed" from Kelly's work, as 26 of the 28 footnotes are references to his articles.<sup>58</sup> Kelly commented on many of the directives in the 1958 edition of *Medical-Moral Problems*.

Also very popular was his pamphlet, *Modern Youth and Chastity*, that he began writing in 1940 and published in 1944 (although it went through many revisions afterwards).<sup>59</sup> The pamphlet and book sought to explain Catholic teachings on chastity and to advise young people on how to engage in healthy friendships and relationships.<sup>60</sup> Originally intended for Catholics, it was later revised to be more inclusive. The pamphlet was printed until 1963, by which time it had been translated into five languages and reproduced into over one million copies.<sup>61</sup> In these ways, Kelly's writings were quickly integrated into the lives of many people.

Despite these successes, Kelly was not well received by all of his contemporary theologians. In his 1964 *Commonweal* article "Authority and the Theologian," Daniel Callahan commented on Ford and Kelly's book<sup>62</sup> and acknowledged, "on the whole they have steered a middle course between the arch-reactionaries and the pioneers."<sup>63</sup> However, Callahan criticized them for their conclusions against artificial contraception. He summarized their method and then berated them for focusing primarily on papal documents, scholastic philosophy, and canon law. Callahan noted their sensitivity to couples faced with hardships in relation to contraception. Perhaps precisely because of

their sensitivity to this struggle, Callahan found Ford and Kelly's conclusions unfitting. He stated that their work "is years behind the revolution now in progress."<sup>64</sup> Also egregious to Callahan was what Kelly and Ford's method revealed about their understanding of the role of the theologian. Callahan likened them to "civil servants."<sup>65</sup> His strong criticisms were not lost on Kelly. According to Lisson, Ford claimed that Kelly suffered from very low-blood pressure in the days following the heart attack that would precipitate his death. When no medications could help him, the only thing that would raise Kelly's blood pressure was to say Callahan's name.<sup>66</sup>

Looking back at Kelly's legacy, some modern historians agree with Callahan. As Keenan notes: "In a significant study of Catholic medical ethics in the United States in the 20<sup>th</sup> century, David Kelly identifies the period from 1940-1968 as 'ecclesiastical positivism.'<sup>67</sup> Keenan remarks that Ford and Kelly easily capitulated to *Humane Vitae*, turning a blind eye to conscience formation and progress made in theology up until that point.

## V. Conclusion

Regardless of one's opinion of him, Gerald Kelly was a complex figure who left an indelible mark on Catholic medical ethics. Kelly's lessons are relevant to modern Catholic health care ethics, which not only shares a history with Kelly, but also shares with Kelly a commitment to creating efficacious and well-founded health care policies that are in dialogue with magisterial teachings. In the issue of end-of-life care, Kelly displayed great medical, analytic, pastoral, and theological

acumen. He was critical to clarifying the understanding of ordinary and extraordinary means in end-of-life care. His understanding of the distinction shapes how we understand the concepts today.

Many of Kelly's methods are also relevant today. His emphasis on surveying a bioethical controversy reminds us to generously read and assess the range of views on bioethical issues. Kelly took seriously the debates on an issue and he investigated what issues were at the heart of a controversy. He also offers some useful insights for Catholic health care ethicists today who take seriously the ERDs, bishops' statements, and magisterial decrees. When interpreting magisterial documents, Kelly was careful not to exaggerate the point of the decree. He paid close attention to the history informing the pope's articulation of the problem and its subsequent solution. Acknowledging what historical event or issue the pope was responding to allowed Kelly to confine the scope of a decree. Kelly also sought to find the most reasonable interpretation of the pope's teaching. For instance, when interpreting the principle of totality, Kelly interpreted the word "necessity" broadly because the alternative was nonsensical. Kelly also assumed the pope was aware of controversies and so an absence of papal clarity indicated the appropriateness of a diversity of opinions.

Problematically, though, Kelly shied away from educating others when it was difficult. For instance, Callahan reminds us that Kelly simply reiterated the papal stance on birth control and artificial insemination rather than explaining them. Kelly's own method of investigating the controversy and looking at the historical context would have served him

well in those areas, as it would have given him an opportunity to explain teachings that were poorly understood and poorly received. Kelly also opted to limit doctors' moral choices, rather than engage in training and teaching doctors. He sought to rescue physicians from personal discernment and instead offered them a clear course of action. As an alternative to this approach, Catholic health care ethics should empower health care professionals with training in ethics. Ethics boards are also ways to encourage thoughtful ethical decision-making done on a group level. Kelly's missteps are good reminders for health professionals today to face difficult questions with rigorous engagement and education.

Despite these shortcomings, Kelly leaves us with an efficacious method for bioethical engagement — survey the controversy and interpret church documents reasonably and within their historical context. He also refined the lasting distinction between ordinary and extraordinary means. Finally, Kelly reminds us that morality and medicine are intertwined. He asserted, “Good medicine is good morality” and “only good morality is good medicine.”<sup>68</sup>

This is the complex legacy of the father of modern American Catholic medical ethics, Gerald Kelly, S.J.

<sup>1</sup> James F. Keenan, *A History of Catholic Moral Theology in the Twentieth Century: From Confessing Sins to Liberating Consciences*, 1st ed. (Continuum, 2010), 115.

<sup>2</sup> Ibid.

<sup>3</sup> See Eric Marcelo O. Genilo, *John Cuthbert Ford, SJ: Moral Theologian at the End of the Manualist Era* (Georgetown University Press, 2007), 1.

<sup>4</sup> Albert R. Jonsen, *A Short History of Medical Ethics* (Oxford University Press, 2000), 93.

<sup>5</sup> Aaron L. Mackler, *Introduction to Jewish and Catholic Bioethics: A Comparative Analysis* (Georgetown University Press, 2003), 88.

<sup>6</sup> The following information is gathered from Edwin L. Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.* (PhD diss, Pontifica Universitas Gregoriana Facultas Theologiae, 1975). 141-215. See also Figure 1: Lisson, "A Chronological Bibliography of the Writings of Gerald A. Kelly, S.J: Books and Articles."

<sup>7</sup> Ibid. 142. "Irish ghetto" is the phrase Kelly used to describe his hometown to Lisson in a Sept 10, 1974 interview..

<sup>8</sup> Ibid. 205.

<sup>9</sup> Ibid. 157.

<sup>10</sup> Genilo, *John Cuthbert Ford, SJ*, 1. See also Keenan, 115.

<sup>11</sup> Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.*, 471. *Medico-Moral Problems* was first released as pamphlet editions in 1949, 1950, 1951, 1952, 1954; the book version was published in 1958. See also Figure 1, Lisson "A Chronological Bibliography of the Writings of Gerald A. Kelly, S.J: Books and Articles."

<sup>12</sup> Ibid. This was written with Ford. Volume 1 was published in 1958 and Volume 2 was published in 1963.

<sup>13</sup> Ibid., 209.

<sup>14</sup> These ideas would be reiterated two years later in Volume I of his co-authored book with Ford, *Contemporary Moral Theology: Questions in Fundamental Moral Theology*.

<sup>15</sup> Gerald Kelly, S.J., "The Morality of Mutilation: Towards a Revision of the Treatise," *Theological Studies* 17, no.3 (1956), 324.

<sup>16</sup> Ibid., 325.

<sup>17</sup> Kelly, S.J., "The Morality of Mutilation: Towards a Revision of the Treatise," 325-326.

<sup>18</sup> Ibid., 326.

<sup>19</sup> Note the exception in the controversy of contraception wherein Ford and Kelly advocated for a consistent stance on the issue, whilst the church did not possess such a stance. This is regarded as an instance when they went beyond what the Magisterium had said (Keenan, 115).

<sup>20</sup> Gerald Kelly, S.J., "Notes: The Duty to Preserve Life," *Theological Studies* 12, no.4 (1951): 555.

<sup>21</sup> Keenan, *A History of Catholic Moral Theology in the Twentieth Century*, 115.

<sup>22</sup> Kelly, S.J., "The Duty of Using Artificial Means of Preserving Life," 204.

<sup>23</sup> Ibid.

<sup>24</sup> Ibid.

<sup>25</sup> Ibid., 206.

<sup>26</sup> Ibid., 207.

<sup>27</sup> Ibid., 220.

<sup>28</sup> Ibid., 216.

<sup>29</sup> Ibid., 218.

<sup>30</sup> Ibid., 218. Note that Kelly juxtaposes his conclusion with that of Fr. McFadden who concludes that the stimulant is not obligatory because it is an extraordinary means (218).

<sup>31</sup> Ibid., 219.

<sup>32</sup> Ibid.

<sup>33</sup> Ibid.

<sup>34</sup> Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.*, 172.

<sup>35</sup> Kelly, S.J., "Notes: The Duty to Preserve Life," 550.

<sup>36</sup> Ibid.

<sup>37</sup> Kelly, S.J., "Pope Pius XII and the Principle of Totality," 373-374.

<sup>38</sup> Ibid., 374.

<sup>39</sup> Ibid., 377.

<sup>40</sup> Ibid., 375.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid., 376.

<sup>43</sup> Ibid., 380.

<sup>44</sup> Ibid.

<sup>45</sup> Ibid., 382.

<sup>46</sup> Ibid., 385.

<sup>47</sup> Ibid., 386.

<sup>48</sup> Ibid., 386.

<sup>49</sup> Ibid., 388.

<sup>50</sup> Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.*, 154. Note that I have access only to the *TS* article. I

do not have access to the other articles cited in this section and so the following information is taken from the description of the articles offered by Lisson.

<sup>51</sup> Ibid., 155.

<sup>52</sup> Ibid.

<sup>53</sup> Ibid., 156 (Lisson cites that this is taken from a quote on page 113 of the article in *American Ecclesiastical Review*).

<sup>54</sup> Ibid., 167. (Lisson cites that he is quoting from page 45 of Kelly's article).

<sup>55</sup> Gerald Kelly, S.J., "Notes on Moral Theology, 1949," *Theological Studies* 11, no.1 (1950): 67.

<sup>56</sup> Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.*, 167.

<sup>57</sup> Ibid., 168.

<sup>58</sup> Ibid., 169.

<sup>59</sup> Ibid., 162.

<sup>60</sup> Gerald Andrew Kelly, *Modern Youth and Chastity: A Book for College Men and Women* (The Queen's Work, 1941).

<sup>61</sup> Ibid., 165.

<sup>62</sup> The book: *Contemporary Moral Theology, Volume 2: Marriage Questions*.

<sup>63</sup> Daniel Callahan, "Authority and the Theologian," *Commonweal* 30, no. 11 (June 1964): 320.

<sup>64</sup> Ibid., 321.

<sup>65</sup> Ibid.

<sup>66</sup> Lisson, S.J., *The Historical Context and Sources of Moral Theology in the Writings of Gerald A. Kelly, S.J.*, 202.

<sup>67</sup> Keenan, "Vatican II and Theological Ethics," 17.

<sup>68</sup> Kelly, S.J., "The Morality of Mutilation: Towards a Revision of the Treatise," 334, footnote 33.

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## Ministry Responses to CHA's Ethicists' Survey

*Editor's Note: The following are observations of ministry ethicists on the results of the 2014 Ethicist Survey.*

**Elliott Louis Bedford, Ph.D.**  
**System Director, Ethics Integration**  
**St. Vincent Health, Indianapolis**  
[elliott.bedford@stvincent.org](mailto:elliott.bedford@stvincent.org)

As in the 2008 original, this survey paints an interesting portrait. Ron Hamel expertly calls our attention to the chiaroscuro of individual strokes and trends, most of which raise more questions than providing answers. Particularly stark is the contrast between the present and prospective state of ethicists themselves. Hamel notes: "It seems unlikely that there will be sufficient numbers to replace ethicists retiring in the next five to ten years" (pg. 42). Hamel echoes his original encouragement of pipelines for people to find and contribute to Catholic health care ethics; I too have sounded this trumpet and take this opportunity to do so once again.<sup>1</sup>

At the same time, I raise one point of observation: the canvas of this portrait is limited. Beyond its frame are two considerations which are essential to its full intelligibility and our consideration thereof. The first has to do with the *effect* of ethicists: whether, and to what degree, the current model is successful. One might argue—with good reason—that survey information regarding an ethicist being "valued and integrated" serves as a proxy measure of effectiveness. One might also argue that effectiveness should be

measured upon the conformity of institutional decisions with the various sets of norms, such as the *Ethical and Religious Directives*. Whatever one's answer, it presumes the answer to a second, more fundamental consideration: what is the *purpose* (final cause) of an ethicist? Success implies an objective. Thus, only in the light of purpose can we appreciate the full effect of the portrait upon which we now gaze.

Might this survey be an opportunity to discover again our *raison d'être*, our reason for being? As I understand it, the purpose of a Catholic health care ethicist is to foster the moral identity of the health care ministry of the Catholic Church—that vessel through which we encounter Jesus Christ. In simple terms this means ethicists are culture builders in their Catholic institutions: *ethos* is our vocation and Christ is our object. This disposition aligns with the framework for what has been called by Popes St. John Paul II, Benedict XVI, and Francis, the "New Evangelization."

This light of purpose brings the issue of decreasing numbers of ethicists into different relief. The numbers are not important *in themselves*, only insofar as they are necessary to achieve the objective better and more effectively. Decreases may not be an existential cause for concern if said ethicists were highly effective in capacitating non-ethicist employees with

theological and ethical competencies and capacities. The survey, self-admittedly, does not measure the efficacy and impact of ethicists in their efforts and presumes their purpose. Perhaps, then, it is time to explicitly reexamine the purpose of a ministry-based Catholic health care ethicist at some future Theology and Ethics Colloquium.

However it is accomplished, I would like to think such ressourcement, carried out under a rubric of the New Evangelization, would reveal a human face of ministry-based Catholic health care ethicist that radiates with “The joy of the gospel [that] fills the hearts and lives of all who encounter Jesus,” the only authentic quality that will attract new members.<sup>2</sup>

<sup>1</sup> Elliott Louis Bedford and Elizabeth Johnson, “Building a Pipeline: Connect Young Talent with the Ministry,” *Health Progress* Vol. 93, No. 3 (May-June 2012): 20-3.

<sup>2</sup> Pope Francis, *Evangelii Gaudium*, no. 1, [http://w2.vatican.va/content/francesco/en/apost\\_exhortations/documents/papa-francesco\\_esortazione-ap\\_20131124\\_evangelii-gaudium.html](http://w2.vatican.va/content/francesco/en/apost_exhortations/documents/papa-francesco_esortazione-ap_20131124_evangelii-gaudium.html) (access 3/20/2015)

**Mary Ann Dillon, RSM, Ph.D.**  
**Mercy Health System, SEPA**  
[mdillon@mercyhealth.org](mailto:mdillon@mercyhealth.org)

In the introduction to the summary of CHA’s 2014 survey of ministry ethicists, Ron Hamel reviewed the initiatives that CHA undertook as a result of reflection upon an earlier (2008) survey. Those initiatives included: the development of desired competencies and qualifications for ministry ethicists, fostering

relationships with graduate students in ethics and developing educational opportunities for mission leaders who either carry out the ethics function or are responsible for ethics in their organizations. Given the results of the 2014 survey, what might CHA do over the next 5 years or so in support of ethicists and the ethics function in Catholic organizations, particularly if, as Hamel suggests (p. 42), “[e]thics is at the heart of mission”? Below are some initial thoughts.

1. **Provide publications, webinars and conferences that respond to the expressed need to integrate a deeper knowledge of and skill in organizational and business fundamentals with the already-honed skills of the practicing ethicist.** As the emphasis on population health quickly moves the delivery of health care beyond the walls of the acute care setting, what are the emerging ethical questions in the wider organizational sphere? What are the key ethical issues that should be addressed as new partnerships are being considered? How are these ethical questions formulated and integrally articulated in specific settings in service to the decision-making process? How do the organization’s leaders develop the needed sensitivities to the wider ethical questions? (It is worth noting that in a CHA 2013 survey, mission leaders indicated a need for similar skills.)

2. **Assist in identifying the most effective place for ethicists in organizational structures in which they often experience themselves as outside the sphere of influence.** How might decision-making processes (e.g. discernment models), particularly around partnerships, new delivery models and so forth, systematically include and engage the ethicist? What are the fora in which ethicists might most effectively contribute? How is the ethicist's role distinct from, aligned with, complementary to and/or confused with the role of the mission leader in a Catholic health care organization?
3. **Attend to the consequences of the changing, perhaps diminishing, role of the ethics committee in the acute care hospital and the implications of the same for ethics sensitivities across the Catholic health care delivery system.** What does that shift signal for the ethicist who often uses the setting of the ethics committee to educate a variety of clinicians? What, if anything, can take its place? In the new world of health care delivery what are the settings in which the ethicist can regularly contribute to the ongoing education of institutional decision-makers as well as nurture the moral conscience of the organization?
4. **Continue to provide a "safe forum" in which the ethical dimensions of new reproductive technologies and other emerging medical practices can be explored.** Where do

practicing ethicists in Catholic institutions find support and challenge in dealing with thorny questions? Do they sometimes struggle with the sense that they are perceived by some as merely the gatekeepers for Catholic orthodoxy? Can CHA effectively harness the combined experience and skills of ethicists from member organizations to provide insights to the evolution of Church guidance on these matters?

While this list is surely a partial one, perhaps it will stimulate further ideas about the ways in which the role of the ethicist might be strengthened across the ministry of Catholic health care.

**Darren M. Henson, Ph.D.**  
**Regional Officer for Mission and Ethics**  
**Presence Health**  
**Chicago**  
[darren.henson@presencehealth.org](mailto:darren.henson@presencehealth.org)

CHA provides a valuable service to its members with this survey. Having read the results of the previous survey, I eagerly reviewed the results of the most recent one. I summarize my reading of these findings in three points.

First, the retirement avalanche poses significant challenges. For the past two to three decades, the strength of Catholic health care ethics has been built on the shoulders and expertise of these women and men. While dying and rising is a natural part of the Catholic worldview, 30 percent retiring in 1–5 years and only 30 percent remaining in 16–30 years present

a gaping hole. I have long admired ethicists in the retiring cohort. Some I consider mentors. Thus, this survey comes with a sense of impending loss. The survey does not uncover the hopes and possible contributions of these retiring ethicists. Many retirees are most impactful in their field once freed from the limits of organizational structures. I urge these ethicists to respond boldly to the fertile opportunities before them. They are poised to respond well to another need noted in the survey, namely, adding to the academic literature. Further, those retiring could become valuable mentors for younger ethicists, both those working and those in graduate programs.

Second, the data reflect a shift in educational backgrounds on two fronts. One is the movement from theological to more philosophical ethics. The second is the shift from a doctorate to a master's degree as essential preparation. Only 30 percent viewed a Ph.D. as essential. I wonder whether pragmatism and utility are finding their way into the profession. Increasingly, I am convinced that Catholic health care ethicists, along with mission leaders, function as missionaries in a foreign land. We cannot presume a flourishing Catholic culture in our institutions. Modernity profoundly shapes the landscape of health care. *Gaudium et Spes* noted the increasing scientific spirit in the world influenced by math, technology, and economics (GS, §§5, 63). Clinical ethics alone cannot adequately confront these cultural currents. The rigors of a doctoral program expose students to a breath and depth of reading.

A good program and competent directors will make students contend with the themes, blessings, and challenges of the enlightenment. Such critical thinking is necessary to change cultures and to effect systemic change, particularly if it aims to sufficiently cohere with the Catholic tradition.

Third, matters of cooperation and analyzing business partnerships have occupied much of ethicists' time. The somewhat esoteric theological Principle of Cooperation has received much attention in the past two decades particularly by theologians in Catholic health care (yet barely taught in graduate programs). Cooperation is not going away. If anything, highly complex arrangements will increase. This, combined with my previous point on education, concern me. These realities call for the deepest, richest aspects of the Catholic theological tradition. Theologians uniquely possess a depth and expertise with regard to the tradition. They think within the tradition, not about the tradition. Fewer theologically informed perspectives may stymie our ability to adequately address the emerging complexities.

As Catholics, the paschal mystery forms us to believe time and again in the promise of new and abundant life. While concerns hover over these data, I am reassured by the work of the CHA to address this reality. I find strength in the work and writings that our senior ethicists have performed. Finally, I am reassured by seminal efforts to cultivate young scholars and ethicists. Though small in size, I have

encountered enthusiasm and commitment from younger colleagues. This offers fertile ground for the Spirit to bring forth new life.

**Amy Martin, Ph.D.**  
**Director, Clinical Ethics**  
**Presence Health**  
**Chicago**

[Amys.martin@presencehealth.org](mailto:Amys.martin@presencehealth.org)

The 2014 CHA follow up survey on ethicists in Catholic health care provides interesting and specific detail about who we are and what we do. The results are not surprising. They suggest that we are older, well educated, not diverse, and we have a vast amount of responsibility, both organizational and clinical.

One thing this snapshot of Catholic ethicists is lacking is detail concerning our gender make up. While it is noted that the field is predominately male with men making up 62 percent of the profession (and thus 38 percent female), no other gender specific information is discussed.<sup>2</sup>

Due to considerable discussion recently about “the gender pay gap” in the mainstream media, many questions arise that could be answered by the survey results. Is “the gender pay gap” something that exists for Catholic ethicists? What are female ethicists earning on average? More precisely, how much are female ethicists in the same role as their male counterparts earning?

Similarly, what is the gender make up of leadership roles of Catholic ethicists?

From the survey, we see that the titles ethicists hold vary greatly, so much so that a large number of people answered “Other.” It makes it quite unclear as to whether our titles match our roles. Yet within the health care leadership structure, title and role are rarely uniform from system to system. Nor can we expect our roles as ethicists to be uniform in the way a nurse’s job is generally from hospital to hospital, operating room to operating room, or ICU to ICU. Yet, regardless of specific title, there are clearly senior leadership roles, especially within regional and national systems. More than likely, these senior leadership roles are represented in the survey by the titles of VP and Senior VP. It would be interesting to know for instance, of the 15 percent who are VP or Senior VP titles, what percentage are females?

If we want to attract the next generation to this vocation, we need to demonstrate that there is no great disparity in compensation and/or leadership roles between genders. As this generation of leaders in ethics begins to build a succession plan and mentor the next generation of leaders, it is important that we see more females begin to take on leadership roles.

**Susan McCarthy, MA**  
**System Director, Clinical Ethics**  
**Ministry Health Care**  
**Milwaukee, Wisc.**  
[Susan.mccarthy@ministryhealth.org](mailto:Susan.mccarthy@ministryhealth.org)

With nearly 40 percent of currently working ethicists over age 60, and only

31.4 percent having a succession plan, there is a clear area of concern for the future. A hopeful sign is the ever-increasing number of graduate students in ethics programs attending conferences. The disadvantage is that some of those students lack experience in health care delivery. Fellowships and similar opportunities can give them some practical experience in ethics case consultation, and in recent years there are many, many more opportunities for formal training in that area.

A different model that can deliver effective system ethicists is to develop the skills and provide formal education to an employee with experience in health care who shows interest and potential in the ethics discipline. This approach, while it requires time and foresight for succession planning, can produce a well-rounded system ethicist with the credibility to be immediately effective. Another approach is to develop local ethics champions. They work a bit like physician extenders/mid-level providers. In our system they are members or chairs of facility ethics committees from a range of disciplines who have developed their skills through additional education and practice. They are known within their institutions as ethics issue resource persons, and can handle many common issues without the involvement of the system ethicist. This model has allowed for a sound ethics service across a 15-hospital system with only one full-time ethicist.

Regarding the “status” of ethicists within the organization, I would tend not to

make too many assumptions. Title is less important in some organizations than in others. In my large regional system, before we became part of Ascension Health, there were only a few system-level VPs. Informal conversation with mission and ethics leaders in other organizations suggests that the VPs in many places earn less than the system directors with comparable positions and scope of responsibility in our organization. As was rightly pointed out, not sitting on the senior leadership team should not necessarily be construed as lacking influence. Ethicists can and do make themselves relevant by being in close relationship with the Senior Mission VP. Those with a robust ethics practice probably find that they have neither the time nor the interest in being a regular member of the system’s senior leadership group, but welcome the opportunity to be involved in organizational issues when called upon.

I was surprised to note that there was no mention of skills in conflict resolution, consensus building, or team leadership listed among the top required competencies, though perhaps those skills are understood to be included in the general term “communication skills.” While the theological underpinnings are essential to understand, without the ability to work collegially with others in solving the day-to-day dilemmas that face every health care system, facility, and department it would seem nearly impossible to be an effective force.

**Mark Repenshek, Ph.D.**  
**Senior Director Ethics Integration and Education**  
**Ascension Health**  
**Healthcare Ethicist**  
**Columbia St. Mary's**  
**Milwaukee**  
[mrepensh@columbia-stmarys.org](mailto:mrepensh@columbia-stmarys.org)

My initial inclination was to respond to the 2014 CHA follow up survey on *Ethicists in Catholic Healthcare* focusing on the issue of diversity. It is clear from both the 2008 initial survey as well as from the follow up, the field remains quite racially and ethnically homogenous. However, I believe Dr. Angove, et al., offer an excellent examination of this issue and potential implications in a previous issue of *Healthcare Ethics USA* v. 22, no. 4 (Fall 2014). Instead, I wish to focus on a shift that occurred in the survey results from 2008 to 2014 in the area of “Roles and Responsibilities” for Catholic health care ethicists.

Dr. Hamel notes that in the 2014 survey “the most significant difference [in ethicists’ roles and responsibilities] is that in the 2008 survey, working with ethics committees ranked second, whereas in the most recent survey, it came in much lower.” Although this may raise some interesting concerns in relationship to a number of other areas within the 2014 survey, I would like to suggest an alternative hypothesis. One optimistic explanation for this change in role and responsibility of the ethicist may be that the survey came out at a time where health

care institutions/systems were just beginning to better understand the implications of population health. The tectonic shift in focus from the episodic care of individuals with acute health needs to the health of entire populations rightly impacts the way we think about the traditional roles and responsibilities of ethics consultation and ethics committees—a traditionally acute care focused consultation structure.

I believe it is of significant relevance to this idea that when ethicists were surveyed in 2014 as to “how ethics might contribute most to their organization in the next 3-5 years,” that “providing new ways of offering ethics services in new models of care” emerged. Along with the next most frequently mentioned area of organizational impact, that is, “nurturing a strong ethics culture and ongoing ethics education to empower various individuals and groups (including medical residents and nurses),” it may be that the more traditional role of educating the ethics committees within the institution is no longer seen as the most effective way to disseminate ethics knowledge and resources throughout the organization—even when considering clinical ethics resources at the bedside. To be clear, I am not suggesting that this work is unimportant or nonessential (in fact, I believe quite the contrary). What I am suggesting though is that population health has pushed ethicists to re-think traditional models of organizational education and integration beyond their own influence on a particularly acute care focused committee structure. This insight

is affirmed in the survey itself, wherein ethicists' view their own contribution to the ministry in the next 3-5 years, by "... finding ways to integrate ethics across the continuum of care and re-thinking our ethical frameworks in light of the shift in emphasis beyond the acute care setting."

I am further encouraged by the findings in the 2014 survey that suggest that "what experience future ethicists will need in order to be effective in the ministry,...most frequently cited [were] clinical experience and previous work in a health care setting." The timeliness of this insight is only highlighted in the survey where it indicates "familiarity with the fundamentals of business and strategy, operations, and how to interface with senior leaders" as a critical experience platform from which future ethicists should launch their career development. At a time where health systems themselves are creating new organizational structures to address the needs of caring for populations across the continuum of care, the operational experience of being embedded within this changing environment is invaluable.

Yet, amidst all the changed responsibilities noted in the shift from the 2008 survey to the 2014 survey, I am concerned that time is not afforded the re-thinking of ethics integration seen as so critical over the next 3-5 years. In other words, it seems from the survey that although role responsibilities are shifting for ethicists, those responsibilities comprise "...church relations, executive formation, analysis of new affiliations and partnerships, mission

due diligence, organizational ethics issues, etc." In the flurry of mergers and acquisitions, can we as a field find time to rethink our work? Amidst the compendium of new demands, will we find time to creatively integrate ethics into new delivery systems that will require new structures for ethics consultation and education? Will we be able to create the vision that ethics committee structures need to develop in order to bring ethics consultation proactively to the clinical team, patients, families *and community*? I believe the juxtaposition of survey results from 2008 and 2014 requires we find this time. The survey itself called out from the membership of our profession a desire to rethink our work and our traditional structures of institutional influence.

The need to create this time for creatively rethinking our work is even more critical in light of the demographics of our profession. It is my hope that we utilize the wisdom of the near 30 percent of our field that plans to exit the profession within five years—many of whom have witnessed multiple tectonic shifts in health care delivery over their careers—to creatively rethink ethics structures with the shift to population health. In this way, I believe we can achieve a proactive and embedded organizational structure for ethics that moves us toward the care of populations while maintaining a foothold in the traditional acute care setting guided by the very wisdom within our field.

# Notes from One in the Statistical Average of Catholic Health Care Ethicists: Claims, Responses and Personal Journeys

Steven J. Squires, MEd, MA, Ph.D.  
System Director of Ethics  
Mercy Health  
Cincinnati  
[ssquires@mercy.com](mailto:ssquires@mercy.com)

As one who answered CHA's 2014 ethicist survey, I have an interest in how my demographic information and responses compare with that of others. Demographically, I am in the statistical mean (the mathematical average) or mode (most repeated quality). I am male, in my 30s, Caucasian and a lay person. I have two master's degrees (one in education, one in ethics), a doctorate (multidisciplinary Ph.D. in Health Care Ethics), director of ethics title and eight years total experience in Catholic health care ethics, with just over five years of that within Catholic health care systems other than Mercy Health.

Why am I responding to the survey?

First, my education and experience give me a rather different perspective on health care ethics and the survey results. My early background is in student life and student affairs (support services including admissions, diversity and residence life in colleges and universities). Second, I have encountered others' thoughts, questions and perceptions about health care ethicists which is probably also true of many other ethicists. Data from the survey and other sources support my responses to others'

claims, which may be of use even if other ethicists have not encountered the same exact claims and questions. Third, and closely related, this essay may provide a wider context for the CHA's 2014 ethicist survey. Daniel Sulmasy and Jeremy Sugarman use the Wallace Steven poem "Thirteen Ways of Looking at a Blackbird" as a metaphor for the different perspectives and disciplines brought to medical ethics. This essay is yet another view of the blackbird that is, in this case, health care ethics.<sup>1</sup>

My response begins with part of my story, which serves as the basis for my responses to the claims of others that are discussed here. I then respond to the observations about health care ethicists that I have heard. The conclusion identifies common themes and suggests opportunities.

## My Professional Journey

In the article, "Behind Every Face Is a Story," Lee Burdette Williams writes this about college students: "What would happen if we stopped to notice students, ask questions, and actually listen to their responses? ... Their lives are complicated."<sup>2</sup> The same is true for others, not *only* students, including health care ethicists. The observation by Williams is one she defines as a refrain to remain "patient, curious, compassionate."<sup>3</sup>

This refrain is also a beacon for me, warning about the dangers of pigeonholing and stereotyping. For example, it is accurate to categorize me as an ethicist with a still-recent, multi-disciplinary terminal degree within the white, male, layperson majority of Catholic health care ethicists. However, it is an unfair judgment to conclude that I am undeserving (e.g., have not suffered), have not paid my dues, and entered the profession the wrong way (i.e., did not work in health care beforehand and am not a moral theologian, physician, nurse, or other healthcare professional). Dismissing backgrounds such as mine as irrelevant to health care ethics is at best unfair. Yet all of these judgments have been directly levied or inferred in comments.

Also, like many others, I had several academic interests. Experiences in college, including being a resident assistant (RA), ignited a fascination with *ways* people learn, which are not only in the classroom but also over a lifetime. I earned a Master's of Education (MEd) in College Student Personnel – Administration, a track that included emphases on human (student) development, basic counseling skills (topics like active listening, not therapy), program evaluation and assessment, curricula and design, human (student) culture and generational studies, laws, and much more. I was a graduate hall director and a graduate assistant.

Yet, I felt a calling to health care ethics. Working full-time, I enrolled in a master's program, graduating with an MA in Biomedical Ethics and Health Care

Policy. My wakeup call occurred after interviewing for many ethics roles where I received two main messages. I had no experience in health care, so hiring me was a strategic risk employers preferred not to take. I was not a physician, nurse, health care professional, or a health care lawyer, so employers would not create an ethics role (presumably part-time). Some wisely suggested that a doctorate in health care ethics was the only way to transition into health care.

This advice was good. During my doctorate, Trinity Health hired me as the Director of Ethics (a system role) after a short, beneficial and enjoyable apprenticeship with Dan O'Brien at Ascension Health. Mentors encouraged and provided opportunities to gain clinical experience while working in system ethics. Finding my clinical ethics experience enjoyable and rewarding, I joined Mercy Health - Cincinnati where I served as a regional ethicist and, for some time, as a mission leader for two hospitals. I recently transitioned to a system ethics role with Mercy Health (formerly Catholic Health Partners), where I continue to be involved in clinical ethics to the degree possible.

### Claims and Responses

This section of the essay addresses claims about ethicists and Catholic health care ethicists that I have heard or overheard at various times. The claims are relevant to the survey results and vice-versa.

*Claim One: Those doing ethics should have a clinical background in healthcare,*

*presumably to be effective or to be most effective.*

Clearly, most respondents to the 2014 CHA ethicist survey are not medical doctors or registered nurses, either when considering their primary degree alone (e.g., MD ethicists) or in conjunction with additional education (e.g., RN, PhD ethicists).<sup>4</sup> This fact reflects the history of bioethics and health care ethics and professionals doing work within these fields.<sup>5</sup> In the development of bioethics, conference organizers and center founders were researchers, scholars and professionals in medicine, philosophy, and theology.<sup>6</sup> The beauty and challenge of bioethics is its breadth and multidisciplinary nature as noted by Dan Callahan reflecting on the lead up to the founding of The Hastings Center (as quoted in *The Birth of Bioethics*).<sup>7</sup> Bioethics reflects influences from medicine and the health sciences, philosophy, literature, theology, anthropology and sociology, law, psychiatry and psychology, public health, feminist thought, political science and more.<sup>8</sup> Having said this, one cannot make the claim from the survey data that the multidisciplinary profile of ethicists and Catholic health care ethicists *should be* the norm because it *is* the norm.<sup>9</sup>

Similarly, linking ethicists' effectiveness to disciplinary or professional backgrounds (i.e., academic training) seems equally tenuous, as evidenced by the following questions: What makes an ethicist? What standards do we use to gauge the ethicist's effectiveness? Are there differing standards for clinical and organizational

ethics, ethicists in a system or ethicists at the bedside, or between organizations? If so, what are they? How are these attributes comparable? Who is evaluating? Might those in leadership or who evaluate ethicists bring a bias against ethicists with different backgrounds, contributing to critical views toward them?

Callahan stresses that no one discipline should have supremacy because of the need for multiple methods in bioethics.<sup>10</sup> Daniel Sulmasy and Jeremy Sugarman believe the best situation is to have a discipline in addition to the field of bioethics, but do not suggest what the discipline should be.<sup>11</sup> Even in a clinical consult, ethics consultants are aware of their discipline, have a certain amount of cross training (per Sulmasy and Sugarman), and rely on others from different disciplines.<sup>12</sup> What is said of the discipline and of ethics consultation can be equally true of those who practice the discipline and do consults.

Ethicists and others may find themselves in the informal role of mentoring others in bioethics and Catholic health care ethics, similar to many faculty and staff members in higher education who are formal and informal academic advisors. Mentorship and advising in this context have many parallels to informed consent because, presumably, the apprentice is competent and free from duress; the mentor and apprentice discuss information after its disclosure, and the apprentice comprehends and authorizes a decision.<sup>13</sup> Similar to medical decisions, field decisions have gravity because they can significantly alter the course of a

person's life, affecting family, health, finance, geographic location and residency, hopes and aspirations, and more. Also, the risks of 'getting it wrong' in the information disclosure and discussion can be disastrous, and that is, again, comparable to medical decisions.

A way to get it wrong is to make an unfounded claim, such as the one above, which may lead to or perpetuate unfair judgments, expectations or practices. For instance, is it fair for one person to alter their career track to become an "effective" ethicist by way of medical school, residency and an ethics degree if a multidisciplinary ethics degree suffices? What if that person wants to be an ethicist, but not a nurse or physician? What is the message about ethicists from other disciplines? Furthermore, is it an unrealizable standard to ask for experience while not providing opportunity for that experience? Whose responsibility is the experience? Is it the university's, the professional's, the employer's, or all of the above? What if residency programs did not accept medical school clinical rotations as "enough" health care experience? A person has to start somewhere.

*Claim Two: Ethicists make too much money, including those in Catholic health care.*

I would encourage focusing on comparative compensation data that includes similar roles, titles, and the industry in general.

Let's consider the numbers with this in mind. The salary range by ethics role is from \$50,001 to \$450,001, a \$400,000 span, for those ethicists in Catholic health care responding to the survey.<sup>14</sup> For perspective, it may be helpful to consider compensation for mission leaders because ethicists are often in mission departments within Catholic health care. The 2013 CHA Mission Leader Survey revealed a salary range from \$40,000 to \$300,000+, a span of over \$260,000, which appears to be dependent on local, market (regional), or system roles.<sup>15</sup> With reference to titles, the annual, mean wage for "medical and health services managers" in medical and surgical hospitals was \$108,210 in 2013.<sup>16</sup> Other healthcare professionals have similar annual, mean wages (2013 data)—\$77,890 for occupational therapists (OTs), \$82,180 for physical therapists, \$68,910 for registered nurses (RNs), \$95,070 for nurse practitioners (NPs), and \$191,880 for physicians and surgeons (MDs).<sup>17</sup> In fact, at least five of the top ten jobs ranked by the *U.S. News and World Report* in 2015 are healthcare-related, based upon the balance of challenge and stress, opportunities for advancement and good incomes.<sup>18</sup>

Many variables affect wages, as anyone in human resources would attest. Variables include the experience and responsibilities of the individual in the role, title ("rank"), geographic area (cost of living) and education.<sup>19</sup> Pay and role title (e.g., manager, director, vice president) are also linked. In all industries, chief executives have the highest median annual wages (\$168,140), followed by top executives (\$101,650) and then general and

operations managers (\$95,440).<sup>20</sup> Wage variance by geography or region (cost of living) is evident, for instance, when considering all medical and health service managers (e.g., physicians' office, home health, skilled nursing, and so on)—\$118,040 in California to \$118,020 in New York to \$93,190 in Ohio.<sup>21</sup> Another strong correlation occurs between education (presumably highest level achieved) and income, supported by the Bureau of Labor Statistics' median weekly earnings (2013 data)—\$1,714 for those with professional degrees, \$1,623 for those with doctoral degrees, \$1,329 for those with master's degrees, \$1,108 for those with bachelor's degrees, \$777 for those with associate's degrees, and \$651 for those with a high school diploma.<sup>22</sup>

For comparison, the annual mean income for ethicist survey respondents should be about \$76,175.51 to \$88,287.52, with a median around \$250,000 and a mode within the \$75,001 to \$100,000 range.<sup>23</sup> Clearly, the income range between mission leaders and ethicists is close. The same is true for the mean income of ethicists, which is close to the mean of RNs, OTs, PTs and hospital managers. Ethicists have comparable incomes to others in mission, others with similar titles and others within the health care industry.

Lest we confuse Hume's distinction of *is* and *ought*, the claim above judges (*ought not*) without relative observation (*why not*). Consider the innate message about mission, ethics and spirituality if clinical and executive counterparts do and 'should' make more money. Determining income is art and science; inequities may

result. An equitable system for one is not for another because of differing notions of fairness. Unequal pay claims should have specific grounds and concepts of fairness for these reasons, placing responsibility on the person making the claim. A particular *why not* must accompany *ought not* to respond with *why* and *ought*. Otherwise, ethicists' incomes seem equitable, especially if fairness follows similar roles (e.g., mission leaders), titles (managers, directors, vice presidents) and industries (e.g., health care).

*Claim Three: Catholic health care ethicists need to be, or should be, Catholic.*

This issue is of interest to me, having been in different faith traditions. Based upon survey respondents, over one in ten Catholic health care ethicists is not Roman Catholic.<sup>24</sup> One could respond that the claim that ethicists need to be Catholic is not true, based upon this data.

Assumptions are inherent in the claim that being Catholic makes one a better Catholic health care ethicist. We should question and, if need be, challenge foundational assumptions: How does one measure if being more formed in the tradition results in better decisions, behaviors, and/or effectiveness as a Catholic health care ethicist? Do the catechism and worship prepare one to be a good, Catholic health care ethicist? How does one gauge if the person embodies her or his catechesis and worship? It is quite possible that someone who is of a Protestant tradition would, for a variety of reasons, make a better ethicist in a Catholic health care setting than someone

raised and trained in the Catholic tradition.

The actual ethics role, what a person does day-to-day, should inform the helpfulness of being Catholic to that role. Generally, health care ethics is interdisciplinary or multidisciplinary; Catholic health care ethics requires an understanding of Catholic teaching. Roles that, for instance, interface with or have systemic interpretations of the Church may require more advanced understanding (e.g., being Catholic, having a pontifical degree). Thus, the issue goes from categorical (i.e., how Catholic health care ethics and education are similar or dissimilar to religious education and practice) to specific (i.e., how this Catholic ethics role is similar or dissimilar from religious education and practice, and what background is helpful).

Another consideration here is the possibility of someone converting to Catholicism. Certainly, ethics and the Church are replete with examples of religious conversion, for example, Alasdair MacIntyre, St. Elizabeth Bayley Seton, Cardinal Avery Dulles, and St. John Henry Newman. Conversions can be the product of evangelization. As Pope Francis explains, we “are active collective subjects or agents of evangelization... [that takes place] in so many different ways,” such as in word and deed.<sup>25</sup> Catholic health care, including mission and ethics, can be powerful evangelizers. The goal is not conversion, but exemplifying the Gospel message in all that we do, which can have a profound impact.<sup>26</sup>

Experiencing the lived mission profoundly affects employees.

Those who fit well with the mission and values of Catholic health care, including prospective Catholic health care ethicists, also merit consideration. Students and coworkers undergo development (e.g., James Fowler’s *Stages of Faith*, 1981, and Timothy Gibson’s *Proposed Levels of Christian Spiritual Maturity*, 2005), which organizations can nurture. Larry Braskamp comments that, “colleges can actively create conditions and campus environments that foster these oft-neglected dimensions of holistic student development.”<sup>27</sup> Arguably, it is true for Catholic health care and not only for academic ethics programs. An example is the four domains influencing college student development – culture, curriculum, co-curriculum and community – that also may apply to the workplace (with adaptations – culture, education and service, and community).<sup>28</sup> Significant implications exist for students and ethicists who perceive acceptance or rejection by those in Catholic ministries. Ethicists and academics in advisory capacities should keep this in mind along with the disclosure that Catholic health care systems vary in their preferences for hiring Catholic ethicists.

*Claims Four and Five: System ethicists should have clinical ethics experience before going into system ethics. System ethicists without this are undeserving (of their roles).*

Again, I have a personal interest in these claims. Not only did I begin in system ethics, I recently had the experience of

doing clinical ethics in a regional role (along with being a mission leader for Mercy Health – Anderson Hospital and Mercy Health – Clermont Hospital for a lesser amount of time) and transitioning back to more of a system ethics role. My own view of system ethics effectiveness being contingent on clinical ethics experience has changed, landing somewhere in between.

The final claims are connected. Both posit judgments (*ought*) that observation (*is*) can counter. Not knowing the “other” category’s composition in the survey, single-hospital ethics roles (11.8 percent) are minimal when compared with regional (52.9 percent) and national roles (20.6 percent).<sup>29</sup> If survey responses indicate reality, about one in ten ethics roles are in a hospital.<sup>30</sup> There is some ambiguity regarding regional roles--some have more clinical focus than others.

Assuming a Catholic ethics ‘tenure track’ (hospital to regional to system), are we setting an expectation that we cannot honor? It is the hospital ethics roles that are the problem; they simply are not too few for the number of new ethicists that would need them.

Furthermore, I have sometimes heard the system office referred to as “the ivory tower” or “the big house” with home office employees called “out of touch” and transitions to the home office termed as “becoming one of them.” Likewise, I have also heard pejorative comments regarding those “on the floors,” or being “out there” with reference to those in clinical work.

Those in education are generally familiar with the town-gown relationship that describes differences between colleges and universities and the greater community. Often these differences are characterized as the “impractical and plodding academic” and the “sloppy and impulsive practitioner.”<sup>31</sup> These descriptions are actually quite similar to the system/home office-practitioner distinction. Recent business literature as well as some associations are replete with examples of new initiatives and programs to lessen tensions in town-gown relationships.<sup>32</sup> Health care could adopt and adapt these programs and initiatives. Such adaptations could serve to give health care ethicists additional experiences and, at the same time, benefit the health care organization.

An example might be helpful. Acute care operations (e.g., patient experience, departmental goal-setting and execution, operational effectiveness, disaster drills, staffing, patient safety and quality, and so on) were important experiences and learnings I had as a hospital-based mission leader. It was also an awakening for me to the relentless pace of hospitals, offices and clinics, and the heroic resilience of clinical caregivers in a race that is both a sprint and a marathon. Similarly, adopting or adapting recently developed town-gown models to the system/home office-practitioner divide could involve system ethicists in hospital operations (e.g., system ethicists doing a study on informed consent documentation for accreditation readiness in a hospital) or hospital ethicists in system operations (e.g., a clinical ethicist serving as a mission leader for a

centralized function or being part of an education team for a system-wide initiative rollout).

However, over emphasizing experience can also be a danger. Many factors mediate experiences and reasoning, such as our awareness and sensitivities, motivation, character, emotions and resourcefulness.<sup>33</sup> Furthermore, experience—as a part of moral reasoning—does not necessarily translate to moral behavior.<sup>34</sup> The application of clinical experiences and moral reasoning to other work depends on noticing the appropriate experiences, gleaning the correct lessons, being self-reflective of emotions, examining motivations and assumptions, imagining possible solutions by constructing proper comparisons between situations (then and now) and acting congruently. One ethicist may behave wisely in a system setting based on short-lived clinical experiences. Another system ethicist may not act in accord with decades of clinical experiences. Thus, experience may not equip one to respond appropriately in other situations, so it is unwise to overly romanticize experience.<sup>35</sup>

We wind up in the middle, as a result. Is clinical experience helpful to system ethicists? It can be. Is clinical experience necessary? It is only if we can support it, otherwise it's an unrealizable standard. How much such experience? It depends on the person. Are system ethicists without it undeserving? No, although this is an opportunity for growth, as it should be for the many other professionals in health care without health care experience.

## Catholic Health Care Ethics and Nurture of the Personal Journey

A common element in the responses to the above claims includes being careful of assumptions and judgments about health care ethics and Catholic health care ethics. It may well be that non-traditional backgrounds, degrees and experiences have much to offer the doing of health care ethics. Another common theme is the need to focus on the individual gifts of Catholic health care ethicists. Using narrative to tell the stories of ethicists is one way to accomplish this. The monikers for an individual focus are the proverbial tip of the iceberg for substantive thoughts and calls to action, such as Williams' "every face has a story," Ashley and O'Rourke's "prudential personalism," and Elie Wiesel's "not see[ing] any person in an abstraction."<sup>36</sup> Catholic health care can distinguish itself through its inclusiveness of ethicists from many backgrounds. Accommodating the mosaic of ethicists with diverse backgrounds strengthens Catholic health care. The ways or methods we use to "develop and...nourish and support potential candidates" must have an unrelenting focus on the person.<sup>37</sup> This closely relates to being careful about assumptions and judgments because generalizations can obscure uniqueness. Statistically, some are in the average, but all ethicists and their narratives are exceptional. The advantage of Catholic health care is its ability to be pastoral, nonjudgmental and inclusive of its and all ethicists.

- <sup>1</sup> Daniel Sulfas and Jeremy Sugarman, “The Many Methods of Medical Ethics (Or, Thirteen Ways of Looking at a Blackbird),” in *Methods in Medical Ethics*, ed. Jeremy Sugarman and Daniel Sulmasy (Washington, D.C.: Georgetown University Press, 2001), 4-5.
- <sup>2</sup> Lee B. Williams, “Behind Every Face Is a Story,” *About Campus* 3, no. 1 (1998): 16.
- <sup>3</sup> Williams, “Behind Every Face Is a Story,” 16.
- <sup>4</sup> Catholic Health Association of the United States (CHA), “E6 Respondent Education Background,” in *CHA 2014 Ethicist Survey* (slide presentation of survey results, 2014), slide 7.
- <sup>5</sup> For the distinction between a field of inquiry and discipline, see Sulmasy and Sugarman, “The Many Methods,” 5; I often use the term professional to describe ethicists in light of not having a more appropriate term for those in the field of ethics.
- <sup>6</sup> See Albert Jonsen, *The Birth of Bioethics* (New York, NY: Oxford University Press, 1998), 3-122.
- <sup>7</sup> Jonsen, *The Birth of Bioethics*, 20.
- <sup>8</sup> For instance, see Daniel Callahan, “Bioethics,” in *Encyclopedia of Bioethics*, ed. Stephen Post, third edition, vol. 1. (New York, NY: Thomson Gale, 2004), 281-282; Sulmasy and Sugarman, “The Many Methods,” 5.
- <sup>9</sup> See David Hume, *A Treatise of Human Nature*, ed. Lewis Selby-Bigge (Oxford: Clarendon Press, 1986), 469.
- <sup>10</sup> Callahan, “Bioethics,” 281.
- <sup>11</sup> Sulmasy and Sugarman, “The Many Methods,” 5-6.
- <sup>12</sup> Sulmasy and Sugarman, “The Many Methods,” 5.
- <sup>13</sup> For elements of informed consent, see James Tubbs, *A Handbook of Bioethics Terms* (Washington, D.C.: Georgetown University Press, 2009), 85.
- <sup>14</sup> Catholic Health Association of the United States (CHA), “CE15 Salary Range for Current Position,” in *CHA 2014 Ethicist Survey* (slide presentation of survey results, 2014), slide 16.
- <sup>15</sup> Brian Smith, Patricia Talone, John Reid, and Maureen Gallagher, “New Survey: Mission Leaders Respond – Executive Summary of the 2013 CHA Mission Leader Survey,” *Health Progress* 94, no. 6 (2013): 74.
- <sup>16</sup> U.S. Bureau of Labor Statistics, Division of Occupational Employment Statistics. “Occupational Employment Statistics—Occupational Employment and Wages, May 2013, 11-9111 Medical and Health Services Managers.” Last modified in 2014. Accessed March 20, 2015. <http://www.bls.gov/oes/current/oes119111.htm>.
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- <sup>24</sup> Catholic Health Association of the United States (CHA), “D5 Respondent Religious Affiliation,” in *CHA 2014 Ethicist Survey* (slide presentation of survey results, 2014), slide 6.

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- <sup>34</sup> Jonathan Friday, “Education in Moral Theology and the Improvement in Moral Thought,” *Journal of Moral Education* 33, no. 1 (2004): 23-33.
- <sup>35</sup> Stephen Brookfield, “Understanding and Facilitating Moral Learning in Adults,” *Journal of Moral Education* 27, no. 3 (1998): 285-289.
- <sup>36</sup> Benedict Ashley and Kevin O’Rourke, *Healthcare Ethics: A Theological Analysis*, third edition (St. Louis, MO: The Catholic Health Association of the United States, 1989), 161; Elie Wiesel, *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation*, ed. George Anna’s and Michael Groin (New York, NY: Oxford University Press, 1992), ix; Williams, “Behind Every Face Is a Story,” 16.
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## More on the ACA and the Right to Health Care

Five years ago, President Obama signed into law the Affordable Care Act. This year the Department of Health and Human Services reports that nearly 11 million people have gained coverage under the bill. Twenty-eight states have expanded Medicaid and CHIP programs to cover nearly 10 million more Americans. While taxpayers have seen the lowest rate of cost increase since 1960, 7 out of 10 Market Place users declared their satisfaction as excellent or good. (“The Affordable Care Act is Working,” DHHS, <http://www.hhs.gov/healthcare/facts/factsheets/2014/10/affordable-care-act-is-working.html>)

Even with these results, court challenges and a rocky website dominate the news coverage while controversy reigns in the halls of the Capitol. President Obama states that it “is working even better than anticipated,” while Speaker of the House John Boehner disagrees, saying it’s a “legacy of broken promises.” (“CDC: 11M Fewer Uninsured Since Obamacare,” *USA Today*, March 24 2015). Whichever way one falls on the political spectrum, we have a long way to go until all Americans have access to health insurance. National Public Radio finds that 13.2 percent of Americans are still without coverage at the beginning of 2015. Meanwhile very many of the nearly eight million new Medicaid recipients “must wait for months or travel long distances to see a doctor” due to network inadequacy and the lack of primary

physicians according to the *New York Times*. (“For Many New Medicaid Enrollees, Care is Hard to Find, Report Says,” *New York Times*, September 27 2014). These are hurdles large enough to question whether the willpower of our lawmakers can overcome political differences. It demands a renewed effort by our leaders to push for continued expansion.

Meanwhile, the ACA is fighting an uphill battle for acceptance. The most recent challenge making its way through the U.S. Supreme Court could have a major impact on the affordability of health insurance for those using Federal Exchanges. *The Washington Times* reporting from the Department of Health and Human Services estimates that nearly 8 million Americans could lose their subsidies if the justices rule against the Administration. *Commonweal Magazine* urges the justices and political leaders to keep federal subsidies intact with their piece titled, “We Would Miss Obamacare.” The writers highlight the positive shifts to insurance affordability and accessibility while expanding the conversation to questions about the common good and the needs of the poor (<https://www.commonwealmagazine.org/we-would-miss-obamacare>).

In 2013 the United States Conference of Catholic Bishops’ Department of Justice, Peace, and Human Development produced a report titled “Access to Health Care.” In it, the bishops remind the faithful that health care “is a basic human right” and “an affirmation of human dignity.” (“Access to Health Care,”

USCCB, <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/2013-02-Health-Care-background.pdf>) The chairman of this group, Most Reverend Thomas G. Wenski, recently wrote another letter to the U.S. Congress concerning the budget. The Archbishop reminds leaders that the “moral measure of the federal budget is not which party wins or which powerful interests prevail, but rather how those who are jobless, hungry, homeless, or poor are treated.” (“Letter To Congress On Federal Budget Resolution For Fiscal Year 2016,” USCCB, <http://www.usccb.org/issues-and-action/human-life-and-dignity/federal-budget/letter-to-congress-from-archbishop-wenski-bishop-cantu-on-federal-budget-fy-2016-02-27-2015.cfm>).

Catholic magazines and online forums have brought this conversation to the wider faith community. The cover of *US Catholic's* March issue highlight this very concern with Murphy-Gill's piece, “Uncovered: Who's Still Not Getting Health Insurance.” She brings to light the neediest in our communities: migrant workers, undocumented families, and those with mental illness. These populations remain outside the umbrella of the ACA. Another concern exists for those who do qualify but are “still on the hook for deductibles that can top \$5,000 for individuals and \$10,000 for families” (“Unable to Meet Deductibles or the Doctor,” *New York Times*, October 17 2014). These recipients are then unable to afford the deductible cost while still paying for the monthly premiums - a very difficult financial situation for those in

need. *No* doubt readers and others in the ministry continue to see members of these groups enter their facilities without proper health insurance or the inability to pay their deductible. It is a population with unique challenges, but one that deserves our attention. For resources on how to help in one's local facility, see CHA's e-module “Welcoming the Stranger.”

*America Magazine* questions the current discussions happening within Congress. The website recently printed a piece titled, “Bishops Say, Protect the Poor.” The Jesuit online publication reports the cuts to Medicaid and CHIP programs proposed by current Congressional leaders. The writers of the article remind us all, “that the needs of hungry, homeless and unemployed people must be the country's highest priority.” (“Bishops Say, Protect the Poor,” *America Magazine*, April 2015, <http://americamagazine.org/issue/bishops-say-protect-poor>)

The Catholic Health Association continues to lead the charge for broader access. CHA recently filed a friend-of-the-court brief urging the U.S. Supreme Court to maintain health care subsidies. (CHA, <http://ncronline.org/news/politics/cha-brief-urges-us-supreme-court-maintain-health-care-subsidies>).

As the lawyers battle in the courts and the politicians in the legislatures, American Catholic leaders stand behind the call to heal the sick and help the poor. However the Affordable Care Act lives on, Catholic health care must continue to find ways to

provide the healing ministry of Jesus entrusted to us, especially to those most in need.

Nathaniel Hibner  
Graduate Student  
Albert Gnaegi Center for Health Care  
Ethics  
Saint Louis University

## Of Note

### **Growing Human Kidneys in Rats Sparks Ethical Debate**

The *American Journal of Transplantation* recently published findings from a study conducted by Eugene Gu, a medical student at Duke University and founder and CEO of Ganogen, Inc., and his colleagues. The study obtained kidneys from aborted human fetuses and implanted them into adult rats that lacked an immune system. A month later, the researchers removed the rats' own kidneys. The rats survived an average of four to five months and one survived ten months. Gu's team believes this research could lead to safer methods of drug testing and, ultimately, healthy kidneys for transplantation into humans. This type of research raises several ethical questions. Can researchers use human fetal organs at all and how is consent defined? Is it ethical to implant human organs into nonhuman animals? What kind of oversight is necessary when transplanting kidneys into animals? Arthur Caplan, a bioethicist at NYU Langone Medical Center, is not concerned about the study itself but about the reaction of the American public. "American society is morally uncomfortable enough about abortion that growing organs from fetal remains will never be accepted, and will be banned in state after state."

Tanya Lewis, Jan. 21, 2015,  
Livescience.com

### **Diagnosis of Alzheimer's Disease Often Withheld From Patients, Report Says**

The Alzheimer's Association recently released their 2105 Facts and Figures report. One finding indicated that only 45 percent of those with Alzheimer's were given their diagnosis by doctors or health care providers. The report stated two common reasons doctors withhold the diagnosis: a reluctance to create additional emotional stress and lack of time or training to properly diagnose the disease. Withholding the diagnosis gives families less time to make financial and caregiving plans and ignores the dignity and autonomy of the patient. The report notes that the negative public perception of Alzheimer's is the same as that of cancer decades before. It is estimated that in 2015, 5.3 million people are living with Alzheimer's disease. Direct cost of the disease is estimated at \$226 billion. Frederick Kunkle, March 24, 2015, *The Washington Post*

### **Insurers Squeezed By Aging's High Costs: Paying From Policies for Nursing Homes Draining Profits**

In the 1980s, Genworth made incorrect assumptions concerning how long people live, the cost of health care and interest rates. These errors have led to Genworth raising prices on older long-term care policies and introducing new products to make long-term care insurance a sustainable business. Tom McNerney, Genworth's CEO, says "There's clearly a

very high need for these policies, given high demand and the limited number of insurers offering it today, I think it can be a very good industry going forward.” Genworth is not the only company having to make changes to its long-term care policies. Four of the five largest long-term care insurance providers have decreased their long-term care insurance or stopped selling any new policies. Outside of private insurance, older Americans have few options. Medicare only covers nursing home care stays in certain circumstances and long-term insurance is not part of the Affordable Care Act. Many people are turning to Medicaid to cover the costs but that puts a strain on state budgets. Long-term care insurance providers have learned from past errors and calculated a necessary price for policies but the price may be too high for most people to afford. Matthew Craft, March 29, 2015, *The Blade*

### **Teenagers Face Early Death, on Their Terms**

A new guide, “Voicing My Choices,” has been created for and by adolescent and young adult patients as a way to discuss end-of-life issues and wishes. Lori Wiener, a social worker and principal investigator on the research that led to the guide, said it was created to give young patients a way “to make choices about what nurtures, protects and affirms their remaining life and how they wish to be remembered.” Although parents retain legal authority for underage patients, the guide asks questions regarding medical decisions and comfort preferences. Other sections

include a list of favorite things, visitor protocol and an opportunity for self-description. For some young patients, the guide allows them to assert control which can be therapeutic. The ability to designate their bodies for research and create a ritual for their funeral gives patients the ability to leave behind a legacy. When to give the guide to a patient is still a debated topic. Wiener suggests giving the guide to the patient soon after the diagnosis but when the patient is stable. Waiting too long can result in a patient being unable to physically voice their wishes. Some parents resist the guide because they fear talking about death will bring about death faster. Some patients resist the guide because they do not want to express their true feelings concerning treatment with their parents. Although the guide meets some resistance, it has proven beneficial to some young adults and their families. Jan Hoffman, March 28, 2015, *The New York Times*

### **Disabled Elderly Decline Sharply After ICU**

A new study published in *JAMA Internal Medicine*, examined data on almost 300 patients to determine if disability level affected patient results after being admitted to the hospital intensive care unit (ICU). The study team used a questionnaire of basic life tasks to determine disability levels and accordingly grouped people into one of three categories: minimally disabled, mild to moderate disability, or severely disabled.

The study found that patients with mild to moderate disability were twice as likely as minimally disabled patients to die within one year of ICU hospitalization and the severely disabled patients were three times as likely to die within one year. The minimally disabled patients should be the focus for aggressive rehabilitation since they have the best chance of full ICU recovery. Dr. Lauren E. Ferrante, lead author, stated that surprisingly, “pre ICU function had the same magnitude of effect as a mechanical ventilator.” Dr. Kenneth Covinsky, a clinical-researcher in the University of California division of geriatrics, wrote an editorial to accompany the study. “This study shows that even among those who survive their care in the ICU, rates of disability are very high in the following year ... Older patients and their families need to be prepared for the likelihood that they will be considerably more disabled after an ICU stay.” Kathryn Doyle, Feb.12, 2015, *Reuters*

### **Transplant first: Organ Donation from UK Newborn**

The parents of a six-day-old baby girl agreed to donate her kidney to a patient with renal failure and donate liver cells to a patient with a failing liver. The baby girl had severe brain damage and the intricate surgery occurred when her heart stopped beating. Professor James Neuberger, NHS Blood and Transplant, said “We are pleased the first transplant of organs from a newborn in the UK was a success and we praise the brave decision of the family to

donate their baby’s organs ... The sad reality is for everybody to get the lifesaving transplant they are desperately in need of, more families who are facing the tragic loss of their young child will need to agree to donation.” In the UK, the official waiting list has 15 infants under the age of two currently in need of organs but the numbers may actually be higher. For small children, organs from older donors do not always work but instead successful transplants come young children. The Royal College of Paediatrics and Child Health is conducting an official review. Smitha Mundasad, Jan. 19, 2015, BBC News

### **The Coming Revolution in Much Cheaper Life-Saving Drugs**

In January, a Food and Drug Administration panel recommended the approval of Zarxio, a biosimilar drug of Neupogen, which helps cancer patients fight infection after chemotherapy. Zarxio would be the first biosimilar drug to be approved by the FDA. A biosimilar is similar to a generic drug but instead of being a copycat of a chemically synthesized medication it is a copycat of a biologic. Biologics are complex and costly drugs made from living organisms. The law requires that biosimilars are “highly similar” to the original drug and do not have any “clinically meaningful” differences. Generic drugs offer about 75 percent savings from the brand-name drug but biosimilars will probably offer a 20 to 30 percent savings. The FDA must also decide if biosimilars will require a unique

name or retain the name of the drug they are copying. There are a few factors influencing the approval of biosimilar drugs. Makers of biologics are looking to block approval as they try to protect their drugs and their profits. The health care industry wants approval because it could reduce spending. Those producing biosimilars are concerned about educating patients and doctors about this new drug category. Jason Millman, Jan. 16, 2015, *The Washington Post*

### **Online Offers of Personalized Cancer Medicine May Not Be Trustworthy**

Dr. Stacy W. Gray, a medical oncologist at Dana-Faber Cancer Institute in Boston, is the lead author of a study recently published in the *Journal of the National Cancer Institute*. The researchers looked at 4,910 websites that promoted or sold personalized cancer medicine such as tumor tests and genetic risk analyses. Of the top 55 websites, 56 percent were commercially sponsored. Another 20 percent were promoted by academic institutions and 15 percent by private institutions. Only 2 percent were conducted by individual doctors. The researchers found that only 28 percent of the websites sold tests they would endorse. Most sites described the benefits of their products (85 percent) but only 27 percent specified possible limitations. Evaluating the website's validity is not easy because each site is unique from all the others. Dr. Gray told Reuters, "The take home message for patients and doctors is that they need to be careful and critically

evaluate what they see online. If patients encounter things online they're curious about, they should talk to their providers about whether those tests are helpful."

Janice Neumann, March 11, 2015, *Reuters Health*

*Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, Assistant Director, supervised the contributions of health law students Lauren Rodriguez (J.D. Anticipated May 2016) and Maxwell Murtaugh (JD anticipated May 2015).*

### **Guatemalans Deliberately Infected with STDs Sue Johns Hopkins**

Experiments similar to the Tuskegee syphilis experiments were conducted in Guatemala during the late 1940s and early 1950s. A lawsuit filed at the end of March 2015 against Johns Hopkins, the Rockefeller Foundation, Bristol-Myers Squibb and Mead Johnson alleges that vulnerable populations of Guatemalan citizens were infected with various sexually transmitted diseases [STD] in order to test the effectiveness of penicillin and other treatments against STDs. This lawsuit seeks more than \$1 billion in damages and follows the 2012 dismissal of a federal class action lawsuit regarding the same experiments but filed against the U.S. government. The lawsuit now pending in Baltimore City Circuit Court alleges Johns Hopkins and the Rockefeller Foundation not only designed, but they

benefitted from the experiments by controlling and influencing the authorized individuals directly dealing with the research of venereal disease.

Ralph Ellis, CNN, April 4, 2015, <http://www.cnn.com/2015/04/03/americas/guatemala-std-lawsuit/index.html>.

### **Giving Out Private Data for Discount in Insurance**

John Hancock Insurance is introducing a program that will apply a consumer's day-to-day fitness activities and health information to the consumer's life insurance policy. This program will be operated in conjunction with global wellness company, Vitality. It is well-known anyone buying life insurance will need to share her medical history, but this program will also ask customers to provide continuous updates on health and fitness activity. John Hancock's program will be a point-based discount and incentive program that might have its consumers answer more personal and sensitive health information to collect points and earn insurance premium discounts. The president of John Hancock Insurance, Michael Doughty, said consumers do not have provide information they don't want to, "[t]he trade-off is you won't get points for that." Questions of whether wellness program address the chronically ill population are already causing speculation of program value. Skepticism as to how the information collected by wellness programs will be protected is apparent as well. John Hancock clarified that the information gathered would not be sold

but it would be shared with entities assisting with the program's administration and could be used to develop new insurance products. Tara Siegel Bernard, *The New York Times*, April 8, 2015, <http://www.nytimes.com/2015/04/08/your-money/giving-out-private-data-for-discount-in-insurance.html?ref=health>.

### **DOJ Settles With Embattled Lab, Criminal Charges for Executives Still Possible**

From a \$47 million payment to a possible \$100 million over time, Health Diagnostic Laboratory, Inc. (HDL) has reached a settlement agreement with the Department of Justice (DOJ) from an investigation dealing with kickbacks, illegal sales, marketing and billing practices. "When health care companies pursue profits by paying kickbacks to doctors, they undermine a patient's ability to trust that medical decisions are being made for scientific reasons, not financial ones," said District of Columbia Acting US Attorney Vincent Cohen Jr. Cohen also said this case demonstrates DOJ's committed to working with whistle blowers to "defend the integrity of the health care system from illegal agreements that hurt patients and taxpayers." Larry Husten, *Forbes*, April 10, 2015, <http://www.forbes.com/sites/larryhusten/2015/04/10/doj-settles-with-embattled-lab-criminal-charges-for-executives-still-possible/?ss=pharma-healthcare>.

### **Health Insurers May Be Finding New Ways to Discriminate Against Patients**

In 2014, two patient advocacy groups filed a discrimination complaint with the Department of Health and Human Services' civil rights division accusing four Florida insurers of forcing "HIV patients to pay up to 50 percent of the cost of HIV medications, even for generic versions." The four insurers were selling their plans on the ACA exchanges, and under the ACA, health insurers cannot charge individuals more or avoid covering them due to preexisting conditions. The idea is that instead of denying sick patients, insurers placed more expensive medications "for certain chronic conditions into the highest-priced tiers of the drugs they cover," which could cause patients to pay a lot more out of pocket. If true, this means health insurers are creating insurance plans with drug benefits designed to "dissuade sicker people from choosing their plans." Some critics of this attack on insurers point out that everyone has access to coverage and that consumers have a wide range of choices to consider when selecting a plan. All plans are also reviewed by both state and federal officials, and one aspect of the review is identifying any discrimination occurring in plans through benefit designs that "discourage enrollment of consumers with specific medical conditions." While the Obama administration has indicated that it would be considered discriminatory for insurers to design plans that place most drugs for specific conditions into the highest tier of costs, there are calls for

stricter enforcement of these standards. Jason Millman, *The Washington Post*, Jan. 28, 2015

<http://www.washingtonpost.com/blogs/wonkblog/wp/2015/01/28/health-insurers-may-be-finding-new-ways-to-discriminate-against-patients/>

### **Eight State Legislatures Debate Adoption of Interstate Medical Licensure Compact**

Eight state legislatures are considering passing uniform legislation that would essentially "make it easier for physicians to acquire licenses in multiple states." These states are Iowa, Minnesota, Nebraska, South Dakota, Texas, Utah, Vermont, and Wyoming. So far, bills have been introduced that if passed would adopt the Interstate Medical Licensure Compact. The final model of the compact was released in September, 2014, and now, in 2015, states are beginning to seriously consider adopting this legislation. The goal is to "streamline interstate licensing" by allowing physicians in a member state to "apply through the compact for expedited licensure in any member state." The way the compact would work is a licensed physician would submit an application to an interstate commission to practice in another member state. The commission would then determine licensure eligibility. If the physician passed the review and paid the applicable fees, they would be issued a license to practice medicine in that particular member state. Advocates for enactment believe the compact protects the public while being a

more effective mechanism compared with the often rigorous licensing rules currently in place. The overarching goal is to create a licensure system that can cater to the needs of “a growing and changing health care market.” Bloomberg BNA 24 Health Law Reporter (HLR) 123, Jan. 29, 2015, [http://healthlawrc.bna.com/hlrc/4237/split\\_display.adp?fedfid=62153082&vname=hlrnotallissues&jd=a0g1t3u0c9&split=0](http://healthlawrc.bna.com/hlrc/4237/split_display.adp?fedfid=62153082&vname=hlrnotallissues&jd=a0g1t3u0c9&split=0)

### **UK Lawmakers Approve '3-parent babies' Law**

Lawmakers in the United Kingdom approved a proposed law that would make them the “first country...to allow a pioneering in vitro fertilization technique using DNA from three people.” However, there still needs to be a vote in the United Kingdom’s upper house before the bill can officially become law. The pioneering technique carries with it the potential benefit of preventing mitochondrial diseases which affect one in 6,500 babies in the United Kingdom and which can cause health issues including blindness and heart disease. Mitochondria problems are passed down from the mother so the technique would allow mothers to have children without passing on the disease. The technique would involve “transferring nuclear genetic material from a mother’s egg or embryo into a donor egg or embryo that’s had its nuclear DNA removed.” The new embryo would then essentially create a “three-parent baby” composed of nuclear DNA from both parents and “healthy mitochondrial DNA from the donor embryo.” Proponents of the law

stress that mitochondrial diseases cannot be cured and can affect several people within a family. Additionally, the procedure does not affect the “child’s appearance, personality, or any other features that make a person unique.” However, the proposal is opposed by some religious leaders “in part because the process involves the destruction of an embryo.” The Church of England understands the importance of this procedure and mitochondria diseases, but is calling for more research and discussion on the matter before “such a serious step” is taken. Laura Smith-Spark, CNN, Feb. 3, 2015, <http://www.cnn.com/2015/02/03/health/uk-ivf-3-person-babies/index.html>

### **Supreme Court Justices Split in Key Challenge to Obamacare Subsidies**

Supreme Court justices appeared to “split along ideological lines” during oral arguments in the case of *King v. Burwell* which involves a challenge to ACA tax subsidies. The challengers argued that a “straightforward reading of the law,” which includes the phrase, “established by the State,” requires individuals to purchase insurance on state marketplaces in order to receive tax subsidies. This interpretation means that individuals purchasing plans on federal marketplaces would not be eligible for tax subsidies. A ruling in favor of this meaning could have a major impact on the millions of “Americans who receive subsidies in the 34 states” that have declined to set up state-run exchanges. The liberal justices

suggested that the law's requirement for federal authorities to setup exchanges when states have declined to do so clearly indicates that "the subsidies follow;" otherwise the ACA's goal of universal health care would be impossible. This line of argument focused on placing, "established by the State," in the context of the ACA as a whole. The conservative justices, on the other hand, asked why did Congress use this specific terminology instead of "under this the act" if it did not intend for it to literally mean "by the State." They focused on implementing the actual statute as written and not twisting words to achieve the statute that Congress intended to create. While the decision will have a major impact on the ACA's viability, a final decision will likely not be ready until sometime in June. Robert Barnes, *The Washington Post*, March 4, 2015

[http://www.washingtonpost.com/politics/courts\\_law/obamacare-back-before-high-court-today/2015/03/03/6dff31a4-c1ec-11e4-9271-610273846239\\_story.html](http://www.washingtonpost.com/politics/courts_law/obamacare-back-before-high-court-today/2015/03/03/6dff31a4-c1ec-11e4-9271-610273846239_story.html)

### **Missouri Health Care Navigator Law Pre-empted, Court Rules**

The 8th Circuit Court "blocked some parts of a Missouri law" which restricted the type of information navigators and certified counselors could provide to those trying to obtain health insurance under the ACA. This ruling was in response to a challenge to a 2013 Missouri law that prevented navigators and certified counselors from giving advice on choosing an insurance plan. The law also prevented

counselors from talking about plans that were not on the federal website and required "counselors to direct consumers who have had insurance through an agent or broker to talk to an insurance provider instead." This essentially reduced the amount of assistance counselors and navigators could give to those trying to find health insurance. The 2013 restrictions created a situation of uncertainty where many counselors were unsure what information qualified as prohibited advice such as whether advising people to apply for Medicaid would violate the law. The 8th Circuit held that these limitations conflicted with and thus were superseded by federal law which permitted such advising. The court did find, however, that Missouri could implement "licensure requirements for navigators and counselors," but they could not limit or control the type of information discussed or provided. While this ruling is Missouri-specific, many hope that other states will follow this lead. Associated Press, *The New York Times*, April 10, 2015  
[http://www.nytimes.com/aponline/2015/04/10/us/ap-us-xgr-health-overhaul-navigators.html?\\_r=0](http://www.nytimes.com/aponline/2015/04/10/us/ap-us-xgr-health-overhaul-navigators.html?_r=0)

# Health Care Ethics USA

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